

The background of the cover is a faded, aerial-style map of London, showing the city's street grid and landmarks. On the left side, there is a vertical strip that provides a more detailed and colorful view of a specific urban area, likely the City of London, with red and yellow streets and a prominent building.

# **London Journal of Critical Thought**

Volume 4 Issue 1 June 2021

The London Journal of Critical Thought  
Volume 4, Issue 1 (June 2021)

**Managing Editor**

Victoria L Ridler

**Editorial Board**

Chris Henry

Lucy Finchett-Maddock

Craig Lundy

Matt Mahon

Daniel Matthews

Hannah Richter

Federica Rossi

Jonathan Stafford

Ben Turner

Thomas Waterton

Samuel Wilson

**Advisory Board**

Anna Hickey-Moody, University of Sydney

Henry Somers-Hall, Royal Holloway, University of London

Eddie Bruce-Jones, Birkbeck College, University of London

Claudia Aradau, King's College, University of London

Elena Loizidou, Birkbeck College, University of London

Matthew Charles, University of Westminster

Supported by the School of Law, Birkbeck, University of London

The **London Journal of Critical Thought** is an open access and peer reviewed academic journal that publishes 'collections' of short pieces that emerge in conversation from participation in the London Conference of Critical Thought (LCCT). The LJCT is distinct from a traditional proceedings journal in that the pieces are not framed as stand-alone work, but rather a part of its particular collection.

All articles are © 2021 by the author(s). This work is licenced under a Creative Commons Attribution-ShareAlike 4.0 International License.

<http://londoncritical.org/journal>

ISSN 2398-662X

## Contents

<i>Introduction: Critical Friends and the Choreographies of Care</i> Jade Vu Henry, Emily Jay Nicholls and Fay Dennis	1
<i>Biomedicine, patients and care-full critique: Modes of attending to gynaecological cancer advocacy</i> Lisa Lindén	9
<i>Feminist Para-Ethnographies: A Proposition for a 'Critical Friendship' Between Embodied Experiences and Microbiome Science</i> Andrea Núñez Casal	21
<i>Choreography of Care</i> Keely Macarow	36

# Introduction: Critical Friends and the Choreographies of Care

Jade Vu Henry, Emily Jay Nicholls  
and Fay Dennis

## Care is in Trouble

“Care” has been defined by feminist thinkers as “a species activity that includes everything we do to maintain, continue, and repair ‘our world’ so that we can live in it as well as possible.”<sup>1</sup> This concept of care has been widely deployed to critique how capitalist societies devalue and erase the mundane emotional and physical labour necessary for living the “good life.”<sup>2</sup> It is argued that practices of care such as child-rearing, eldercare, housekeeping, schooling, nursing and community-building are essential for sustaining a thriving society, yet are poorly remunerated and often delegated to women and persons of color.<sup>3</sup> Joan Tronto contends that the “questions that have traditionally informed the lives of women, and servants, slaves, and workers” have not been considered seriously in Western philosophy and political theory.<sup>4</sup> She has therefore advanced a moral and political theory of care that incorporates “as part of our definition of a good society, the values of caring – attentiveness, responsibility, nurturance, compassion, meeting others’ needs – traditionally associated with women and traditionally excluded from public consideration.”<sup>5</sup>

---

<sup>1</sup> Joan C. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York: Routledge, 1993), 103.

<sup>2</sup> See Carol Gilligan, *In a Different Voice: Psychological Theory and Women’s Development* (Cambridge, Massachusetts: Harvard University Press, 1982); Hilary Graham, “The Concept of Caring in Feminist Research: The Case of Domestic Service,” *Sociology* 25, no. 1 (February 1991): 61–78; Berenice Fisher and Joan Tronto, “Towards a Feminist Theory of Caring,” in *Circles of Care: Work and Identity in Women’s Lives*, ed. Emily K. Abel and Margaret K. Nelson (Albany, New York: SUNY Press, 1990).

<sup>3</sup> Nancy Fraser, “Contradictions of Capital and Care,” *New Left Review* 100, July August (2016): 99–117.

<sup>4</sup> Tronto, *Moral Boundaries*, 3.

<sup>5</sup> Tronto, 2–3.

This enduring feminist commitment to “care” has been taken up by scholars of Science and Technology Studies (STS). Their work attends to what Maria Puig de la Bellacasa describes as the “fragile” and “neglected things” in technoscience.<sup>6</sup> Studies of care in homes, clinics and farms have foregrounded the small acts of “tinkering” that individuals perform to continuously adapt technologies to their situations, while adapting such situations back to their technologies.<sup>7</sup> Other studies of care highlight wider power structures in the design, production and use of science and technology, asking “what kinds of social relations are assumed to be desirable in these scenarios, whose interests are represented, and whose labours are erased.”<sup>8</sup> STS researchers have also taken a more reflexive stance, examining how their own routine practices of researching and writing might strengthen certain technoscientific worlds at the expense of others.<sup>9</sup> This concern with “care-full” academic practice has led to new analytic approaches and experimental forms of writing and visual communication, all aimed at capturing the affective, embodied and material webs of practice that constitute care in technoscience.<sup>10</sup>

The turbulence of the contemporary moment has led to a surge in the number of calls for “care” across the humanities and social sciences, as well as in popular and political discourse. While this momentum could be expected to help subvert and resist the oppressive formations brought about through science and technology, Duclos and Criado have made a compelling argument to the contrary. They claim that care may be losing its political potency due to its conflation with affection

---

<sup>6</sup> “Matters of Care in Technoscience: Assembling Neglected Things,” *Social Studies of Science* 41, no. 1 (2011): 85–106.

<sup>7</sup> Annemarie Mol, Ingunn Moser, and Jeannette Pols, eds., *Care in Practice: On Tinkering in Clinics, Homes and Farms* (Bielefeld, Germany: Transcript-Verlag, 2010).

<sup>8</sup> Lucy Suchman, *Human-Machine Reconfigurations: Plans and Situated Actions*, 2 edition (Cambridge: Cambridge University Press, 2007), 224.

<sup>9</sup> Martha Kenney, “Counting, Accounting, and Accountability: Helen Verran’s Relational Empiricism,” *Social Studies of Science*, 45, no. 5 (2015): 749–771.

<sup>10</sup> Vicky Singleton and Steve Mee, “Critical Compassion: Affect, Discretion and Policy–Care Relations,” *The Sociological Review* 65, no. 2\_suppl (2017): 130–49; Martha Kenney, “Fables of Response-Ability: Feminist Science Studies as Didactic Literature,” *Catalyst: Feminism, Theory, Technoscience* 5, no. 1 (2019): 1–39; Laura Watts, *Energy at the End of the World: An Orkney Islands Saga*, Infrastructures (Cambridge, Massachusetts: The MIT Press, 2018).

and positive attachment, serving instead as “a placeholder for a shared desire for comfort and protection” which is all too easily coopted by reactionary politics.<sup>11</sup> The authors have urged researchers to devote more attention to methodologies that support Murphy’s call for the “vexation of care”, in order to foreground how “positive feelings, sympathy, and other forms of attachment can work with and through the grain of hegemonic structures, rather than against them.”<sup>12</sup> Such methodologies in Critical Care studies are better attuned to the ambivalent, contextual and relational aspects of care in technoscience,<sup>13</sup> and can thereby generate scholarship that “stays with the trouble.”<sup>14</sup>

### Thinking Critically with Care

Aligned with this call to reanimate the ethico-political commitments of feminist critical thinking, our Collection will revisit what it means for feminist scholars to “think critically with care”. How do feminist scholars conduct critical studies about care practices? How are such methods “care-full”? How might this strand of scholarship “relate” with wider constellations of critical research traditions across the academy? To explore these questions, we present three reflexive, methodological papers which draw upon our encounters and conversations within this Stream and across the 2019 London Conference of Critical Thought. Each of these contributions demonstrate how care is deployed as a critical analytic, and how the author balances her interrogation *about care* practices, with a commitment *to care* about the human and non-human actors, concepts and relations that she studies. We wish to highlight here three key dimensions of these papers: (1) their attention to lived experience; (2) their fleeting and shifting objects of study; and (3) their reflexive methodological concern with the affective and embodied subjectivities of researchers.

---

<sup>11</sup> “Care in Trouble: Ecologies of Support from Below and Beyond,” *Medical Anthropology Quarterly* 34, no. 2 (2020), 153-154.

<sup>12</sup> Michelle Murphy, “Unsettling Care: Troubling Transnational Itineraries of Care in Feminist Health Practices,” *Social Studies of Science* 45, no. 5 (2015): 719.

<sup>13</sup> Aryn Martin, Natasha Myers, and Ana Viseu, “The Politics of Care in Technoscience,” *Social Studies of Science* 45, no. 5 (2015): 625–41.

<sup>14</sup> Donna Haraway, “When Species Meet: Staying with the Trouble,” *Environment and Planning D: Society and Space* 28, no. 1 (2010): 53–55.

*Lived Experience*

Gathered together at the closing of the 2019 London Conference in Critical Thought, the authors of this collection discussed how our Stream was heavily empirical in comparison with the rest of the Conference presentations. We noted how most presenters in our group had looked to fine-grained ethnographic data to develop their critical research on care practices. As Denzin describes, ethnography aims to “capture the voices of lived experience...details, context, emotion, and the webs of social relationships that join persons to one another.”<sup>15</sup> It is a methodological approach for engaging with “empirical social worlds” which are understood as multi-sited, embodied, affective, sensual and material.<sup>16</sup>

This attunement to such complex and messy worlds is illustrated in the first contribution of the Collection, where Lisa Lindén recounts the lived experiences of gynaecological cancer patients and their families, and how such experiences matter for their involvement in patient activist practices. The second paper by Andrea Núñez Casal documents intimate entanglements of patient, microbe, physician, and researcher in microbiome science, and Keely Macarow’s contribution is similarly attentive to the rhythms of everyday life within eldercare residences. It is through such fine-grained ethnographic case studies that exclusions, ambivalences, and injustices are rendered visible. Rather than “a moral value added to the thinking of things,”<sup>17</sup> these papers aim to avoid abstractions about marginalization and justice, and instead perform their critical emancipatory work through ethnographic engagements with the empirical world.<sup>18</sup>

---

<sup>15</sup> “The Art and Politics of Interpretation,” in *Handbook of Qualitative Research*, ed. Norman Denzin and Yvonna Lincoln (Thousand Oaks, California: Sage Publications, 1994), 83.

<sup>16</sup> See Sarah Pink et al., *Digital Ethnography: Principles and Practice* (London: SAGE, 2015); Tim Ingold, *Being Alive: Essays on Movement, Knowledge and Description* (London: Routledge, 2011); George E. Marcus, “Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography,” *Annual Review of Anthropology* 24, no. 1 (1995): 95–117.

<sup>17</sup> Puig de la Bellacasa, “Matters of Care in Technoscience,” 86.

<sup>18</sup> See also, John Law and Vicky Singleton, “ANT and Politics: Working in and on the World,” *Qualitative Sociology* 36, no. 4 (2013): 485–502.

*Fleeting and Shifting Research Objects*

Thinking critically with care does not end with the foregrounding of marginalized lived experiences, but extends into investigations of how wider “ecologies of practices” enact such exclusions. As Duclos and Criado describe, this approach to critique can generate dynamic “cartographies of the many intersections and frictions between the enveloping and the diverging, the protecting and the containing, the enduring and the engendering, as they play out in care practices”.<sup>19</sup> A second theme emerging from the discussions was the methodological attention to movement and change, and to the *choreographies* that were performed and reified by these feminist scholars as they worked to follow shifting and fleeting objects of study.

In the first contribution, Lindén refers to “choreographies of affect” in researcher practices<sup>20</sup> when describing how she “zoomed in and out”, altering her scale of analysis to “hold on to differences”. The new “feminist para-ethnography” proposed in the second paper by Núñez Casal can also be read as a choreography of the author’s own shifting subjectivities as a woman, patient, microbiologist, cultural theorist and mother. In the third contribution, Macarow looks to the literature in performance and dance studies to define choreography as “the organisation of movement through time and space” as well as the written inscription of that movement. Her exploration of the choreography of care opens up possibilities for connecting the humanities to social science research through the concept of “performance”,<sup>21</sup> and points to the non-representational forms of ethnographic writing championed by anthropologists who “assume that academic and literary genres interpenetrate and that the writing of cultural descriptions is properly experimental and ethical.”<sup>22</sup> In all three papers of this Collection, choreographies of care were adopted by the researchers to capture ambivalences and complexities as well as

---

<sup>19</sup> Duclos and Criado, “Care in Trouble,” 3.

<sup>20</sup> Anne Kerr and Lisa Garforth, “Affective Practices, Care and Bioscience: A Study of Two Laboratories,” *The Sociological Review* 64, no. 1 (2016): 3–20.

<sup>21</sup> Nigel Thrift, “Performance and . . .,” *Environment and Planning A* 35, no. 11 (2003): 2019–2024.

<sup>22</sup> James Clifford, “Introduction: Partial Truths,” in *Writing Culture: The Poetics and Politics of Ethnography*, ed. James Clifford and George E. Marcus (Berkeley, California: University of California Press, 1986), 2.



circulating practices of power and domination.<sup>23</sup>

### *Embodied and Affective Researchers*

An ethnographic engagement with the marginalised - in the spaces between life and death - draws feminist scholars of care into embodied and affective relations with their study participants. All three contributors to this Collection make those accountabilities and responsibilities explicit in their research and writing and reflect upon the authors' positionalities and the politics of their critical research methods. Lindén asserts that it is precisely in the careful manner that she choreographs her analysis, in the way she deliberately shifts her mode of attention, that she expresses and enacts her ethico-political commitments to the worlds of gynaecological cancer. Macarow pushes these embodied and affective relationalities a step further. She reflects on how "signs and failings of our own bodies" might converge in solidarity with our fragile objects of study, via sensual research methods emphasizing "the haptic, sensory, emotional and physical". This form of solidarity resonates with Núñez Casal's account of how decolonialised "critical friendships"<sup>24</sup> are formed between embodied experiences and the sciences, through the process of 'becoming available' described by Vinciane Despret - whereby "the experimenter, far from keeping himself in the background, involves himself: he involves his body, he involves his knowledge, his responsibility and his future."<sup>25</sup>

### **Critical Friends and the Choreographies of Care**

This Collection aims to show how, in the words of Puig de la Bellacasa, thinking critically with care is an "ethically and politically charged practice" and a "material vital doing" which involves tracing empirically how socio-material assemblages gather around "fragile, cherished things"<sup>26</sup>. It is grounded in empirical settings where caring relations are practiced. It requires complex choreography to analyze fleeting and

---

<sup>23</sup> Haraway, "When Species Meet."

<sup>24</sup> Nikolas Rose, "The Human Sciences in a Biological Age," *Theory, Culture & Society* 30, no. 1 (2013): 3–34.

<sup>25</sup> "The Body We Care for: Figures of Anthro-Zoo-Genesis," *Body & Society* 10, no. 2–3 (2004): 130.

<sup>26</sup> Puig de la Bellacasa, "Matters of Care in Technoscience," 90.

shifting registers of care, and to negotiate the embodied and affective interdependencies between researchers and the “researched”. Through such choreographies of care, feminist scholars can also generate “critical friendships” that connect together lived experience, the social and natural sciences, and the humanities.

The event organizers have described how The London Conference in Critical Thought grew from an initial “conversation among friends” who all wished to “embrace emergent thought” in an interdisciplinary community of critical scholars.<sup>27</sup> In this closing section, we would therefore like to reflect briefly on how we, as feminist scholars “thinking critically with care”, might “become available” for “critical friendships” with other traditions of critical thought. That is to say, we wish to close with a vision of how we might “involve” ourselves in the manner described above by Despret: involve our bodies, our knowledges, our responsibilities and our futures, in the making of a larger, collective apparatus for thinking about power, emancipation, and freedom. How might we connect the research in our Collection with other strands of critical thought presented at the 2019 Conference?

To approach these questions, we look to Amy Allen’s discussion of utopia, normativity, subjection and the decolonisation of critical theory.<sup>28</sup> She argues that post-structural strands of feminist scholarship (such as the ones described in this Collection) can enrich our understanding of emancipation by generating a:

precise and specific analysis of domination that illuminates the intersecting and overlapping structures of gender, sexuality, and race with those of class, culture, and postcolonial imperialism, theorised in a transnational frame.<sup>29</sup>

Allen then asserts that the abstract concepts of liberation that are derived from the normative foundations of critical theory can in turn give meaning and hope to these empirical analyses of power, by interpreting “actual lived crises and protests in the light of an

---

<sup>27</sup> “LCCT – LondonCritical,” accessed July 1, 2020, <http://londoncritical.org/about-the-lcct>.

<sup>28</sup> “Emancipation without Utopia: Subjection, Modernity, and the Normative Claims of Feminist Critical Theory,” *Hypatia* 30, no. 3 (2015): 513–29.

<sup>29</sup> Allen, 514.

anticipated future.”<sup>30</sup> While preparing this Collection, we, as feminist scholars of care, have collectively experienced catastrophic fires in Australia, national strikes for UK academics, the unfolding of a global pandemic and the birth of a baby boy. “Making ourselves available” through such affective and embodied experiences, we wish to advocate vigorously for new critical friendships across academia which might care-fully choreograph our “explanatory-diagnostics” of power with the alternative, more “anticipatory-utopian” moments in critical thought.

---

<sup>30</sup> Benhabib, 1986, as cited in Allen, 514.

# **Biomedicine, patients and care-full critique: Modes of attending to gynaecological cancer advocacy practices**

Lisa Lindén

During the last two years I have been doing ethnographic fieldwork with a patient advocacy group from Sweden I call the Gynae Cancer Group (GCG). The group, consisting of cancer patients and their relatives, mobilises to increase public knowledge about gynaecological cancers, intervenes in healthcare and medical research practices, and provides support to fellow patients. As for many other patient advocacy groups, an important part of their advocacy aims to increase and speed up concerned patients' access to new treatments. For example, after several years of advocacy work, in 2018 the GCG succeeded in making the Swedish Cancer Society, which is the largest funder of cancer research in Sweden, to undertake a specific investment in ovarian cancer research. For another example, during 2019 the group pushed for a faster governmental approval of the subsidisation of poly polymerase (PARP) inhibitors – a group of new targeted cancer drugs – to all ovarian cancer patients in Sweden. PARP inhibitors are not a cancer cure, but they might prolong life, and possibly, increase chances of survival.

In the context of care studies in Science and Technology Studies (STS), Jeanette Pols has raised a concern that patient advocacy groups' extensive attention to potential or new biomedical treatments, risks marginalising a continued need to improve care practices concerning ways of living with chronic illness.<sup>1</sup> As some cancers – like ovarian cancer – increasingly are seen as chronic diseases, this is important in this context. Against this backdrop, this paper explores possibilities for

---

<sup>1</sup> Pols, Jeannette. "Knowing Patients: Turning Patient Knowledge into Science." *Science, Technology, & Human Values* 39, no. 1 (2014).

doing “care-full” critique<sup>2</sup> in a context of cancer patient advocacy. My concern is the question of how to tell ethnographic stories “that are *generative* for the people and practices that the stories are about, as well as for the authors and their academic collectives”.<sup>3</sup> For me, this has to do with an ethico-political commitment<sup>4</sup> towards the *politics of* cancer patient advocacy, while at the same time “staying true to” the specificities and generativity of the worlds the representatives of the GCG live in, embody and engage with.<sup>5</sup>

I believe that one possible way of doing care-full critique is to keep asking “how to care?”.<sup>6</sup> This means to not only describe how care is enacted in a specific practice “out-there”, but also, as STS researcher Sonja Jerak-Zuiderent suggests, engage with the question of how we as ethnographers and researchers might care for our scholarly accounts.<sup>7</sup> I engage with this question in this paper. I do so through a theoretical approach that aligns with a Feminist Technoscience Studies “critical care” approach that understands care as a relational doing and an affectively charged and selective mode of attention.<sup>8</sup> In the process of cherishing some things, care also marginalises or excludes other things. In line with this approach, in this paper, I work with a multi-layered

---

<sup>2</sup> In my desire to engage “care-fully”, I am inspired by for example Coopmans’ encouragement of a “care-ful engagement” in how we as STS researchers relate to our own research and fieldwork. See Coopmans, Catelijne. “Caring for Past Research: Singapore, Eye Health Care, STS, and Me.” *East Asian Science, Technology and Society*, 14, no. 1 (2020), 151.

<sup>3</sup> Winthereik, Brit Ross, and Helen Verran. “Ethnographic Stories as Generalizations that Intervene.” *Science Studies* 25, no. 1 (2012), 37.

<sup>4</sup> Puig de La Bellacasa, María. *Matters of Care: Speculative Ethics in More than Human Worlds*. Minnesota: University of Minnesota Press, 2017.

<sup>5</sup> Verran, Helen. “Staying True to the Laughter in Nigerian Classrooms.” *The Sociological Review* 47, no. S1 (1999).

<sup>6</sup> Schrader, Astrid. “Abyssal Intimacies and Temporalities of Care: How (Not) to Care about Deformed Leaf Bugs in the Aftermath of Chernobyl.” *Social Studies of Science* 45, no. 5 (2015), 667.

<sup>7</sup> Jerak-Zuiderent, Sonja. “How to Care for our Accounts?” In Blok, Anders, Ignacio Farias, and Celia Roberts, eds. *The Routledge Companion to Actor-Network Theory*. London: Routledge, 2019.

<sup>8</sup> Lindén, Lisa. *Communicating Care: The Contradictions of HPV Vaccination Campaigns*. Lund: Arkiv Academic Press; Martin, Aryn, Natasha Myers, and Ana Viseu. “The Politics of Care in Technoscience.” *Social Studies of Science* 45, no. 5 (2015): 625-641; Singleton, Vicky, and Steve Mee. “Critical Compassion: Affect, Discretion and Policy.” *The Sociological Review* 65, no. 2\_suppl (2017).

understanding of care that understands it as “an affective state, a material vital doing, and an ethico-political obligation”<sup>9</sup>. I focus both on the care that “we, as STS scholars, teachers, and feminists enact in *our relations with the worlds we study, and that which circulates among the actors in the technoscientific worlds we encounter through our studies*”.<sup>10</sup> I will attend to several layers of care: how I care, how my participants care, and the care practices my participants enact and intervene in through their advocacy.

I explore the question of “how to care for my accounts?” by thinking with the metaphors of “scaling up” and “scaling down”, metaphors I borrow from feminist scholars Lochlann Jain and Jackie Stacey.<sup>11</sup> In incorporating their own cancer narratives in their academic analyses, they shift their mode of attention between a focus on first-person accounts and critical analysis, aiming to “offer readers both critical purchase and affective connection”.<sup>12</sup> Inspired by this, my aim is to explore the question of “how to care for my accounts?” by analytically moving between scales of cancer, scales that together make up some of the current gynaecological cancer worlds. Therefore, in my analysis below, I move between attending to particular, often affective, stories told by the participants in the GCG about their political engagement in the organisation and their relation to gynaecological cancer, whilst attending to larger questions about biomedicine and cancer care. In doing so, I aim to care-fully choreograph my analytical attention, this to tell stories that hold together critical analysis with an affective and embodied engagement, and that aim to speak to the concern for how to care for the accounts we as ethnographers and researchers do of the empirical practices we emerge ourselves in.

### **The patient advocate Caroline**

One of the most active members of the GCG is the patient advocate Caroline. When I met Caroline for an interview in the fall of 2018, she told me that she got involved in the group due to her mother having

---

<sup>9</sup> Puig de la Bellacasa, *Matters of Care*, 42.

<sup>10</sup> Martin, Myers and Viseu, “The Politics of Care in Technoscience”, 626.

<sup>11</sup> Jain, S. Lochlann, and Jackie Stacey. “On Writing about Illness: A Dialogue with S. Lochlann Jain and Jackie Stacey on Cancer, STS, and Cultural Studies.” *Catalyst: Feminism, Theory, Technoscience* 1, no. 1 (2015).

<sup>12</sup> Jain and Stacey, “On Writing about Illness”, 10.

chronic, advanced, ovarian cancer.<sup>13</sup> Caroline also soon found out that she herself is a BRCA mutation carrier with high risk of breast and ovarian cancers, something that further intensified her engagement. She emphasised that she wanted to be involved in the group as “so few people knew about ovarian cancer and I guess I was irritated about that”. “People have not heard about ovarian cancer and I was super angry that my mother’s cancer was detected so late”, she said. As many of the other GCG representatives also frequently have done in interviews, Caroline highlighted that gynaecological cancers are often marginalised in the public and medical spheres; that these cancers are less attended to than, for example, breast and prostate cancers. Therefore, she decided to get involved in the GCG to increase people’s knowledge about ovarian cancer – as well as the other gynaecological cancers – and to push for better care and support, and more research.

During the interview, Caroline said that she sometimes thought about whether she would have the energy to keep being so involved in the group and, as she called it, in “the cancer world”, when her mother has passed away. But, she continued, “I cannot put this world off”. In referring to the breast cancer risk reducing surgery she conducted a couple of years ago, she said, with laughter: “If I take a shower, wait a second, you know, where are my breasts? You are never, you know, free from it”. She continued: “The cancer is always there, nibbling in the background”. Therefore, for her, the commitment to engage in the group is not something she feels she can just “switch off”; it is in a very literal sense an embodied engagement. Her body, her life, is intimately entangled with cancer, and with biomedicine. Her engagement in the GCG, and her commitment to make gynaecological cancers less marginalised, is, in this sense, an “intimate entanglement”<sup>14</sup> that links her own experience and embodiment to biomedicine and to larger questions of the politics of marginalisation and cancer visibility.

During my fieldwork I have gotten to know Caroline. I have learnt that she and her mother are very close, best friends even. I have met her mother, a gynaecological cancer patient advocate herself, several

---

<sup>13</sup> I wrote this article in early 2020 and since then Caroline’s mother has passed away. My thoughts are with Caroline and her family.

<sup>14</sup> Latimer, Joanna, and Daniel López Gómez. “Intimate Entanglements: Affects, More-than-Human Intimacies and the Politics of Relations in Science and Technology.” *The Sociological Review* (2019).

times, and many times I have listened to Caroline talking to her mother on the phone. I have also followed the progression of the mother's cancer. The first time I was supposed to meet Caroline for an interview, she had to cancel the same morning, because her mother was hospitalised and she needed to be there with her. Since then, I realised that when Caroline was not answering emails, then it was likely her mother was ill. I heard several times one of the other board members or volunteers say at meetings that now Caroline's mother is dying, and how imminent it was.

Care is a suitable word to use to describe Caroline's commitment to the gynaecological cancer cause. It is a care for the marginalised, not far from what Feminist Technoscience Studies scholar María Puig de la Bellacasa<sup>15</sup> has called a care for the neglected. Caroline, as do the others in the GCG, care intensely and passionately for a world where gynaecological cancers are publicly visible and easily talked about, where concerned women are provided the best possible care and where no one has to die from these cancers.

In her discussion of advocacy and care, feminist philosopher Lorraine Code<sup>16</sup> highlights that "it makes sense to assume that advocates, singly or as members of an advocacy group, will care about the claims and positions for which they advocate". As Code discusses, the figure of the advocate troubles a vision of a disinterested and dispassionate knower; this vision has to be re-thought when it starts "from situated, vulnerable lives".<sup>17</sup> Learning from this, it makes sense to think about practices of knowing and care as entangled in the context of patient advocacy, and to understand Caroline's engagement in the GCG as such an entanglement. Indeed, care is "a mode of engagement".<sup>18</sup> This engagement, this care, affectively and materially attunes Caroline to medical gynaecological cancer practices in specific ways.

The story of Caroline and her engagement in the GCG exemplifies how the GCG's embodied and intimate care about the gynaecological cancer cause is entangled with politics of cancer.

---

<sup>15</sup> Puig de la Bellacasa, *Matters of Care*.

<sup>16</sup> Code, Lorraine. "Care, Concern, and Advocacy: Is There a Place for Epistemic Responsibility?" *Feminist Philosophy Quarterly* 1, no. 1 (2015), 8.

<sup>17</sup> Code, "Care, Concern, and Advocacy", 18.

<sup>18</sup> Schrader, "Abyssal Intimacies and Temporalities of Care.", 667.



However, as care is a selective mode of attention that allows us to see some things, and not others, the important question is not *if* patient advocates such as Caroline care, but how, what and for whom they care through their engagement and the practices they immerse themselves in. As the GCG enacts and intervenes in practices where it certainly “matters to know and act responsibly and well”<sup>19</sup>, this is important. In the following I will explore advocacy practices in two examples, one focused on new biomedical treatments and one focused on palliative care.<sup>20</sup> These two examples do not only enact strikingly different forms of advocacy practices, but, as I will show, they also require different answers to the question “how to care for my accounts?”.

### **PARP inhibitors**

Social studies of biomedicine and genomics have attended to how high expectations and optimism often are invested in new cancer drugs, and that this risks reducing scientific uncertainties and raise unrealistic expectations.<sup>21</sup> Against this backdrop, in this section I will focus in on the GCG’s practices around “speeding up” the approval of PARP inhibitors as one example of their relation to biomedicine. I do so to relate some of the concerns raised through this form of patient advocacy.<sup>22</sup>

During the autumn of 2019, PARP inhibitors were brought up several times during GCG meetings where I participated as an observer, and I came to learn that PARP inhibitors were strongly cared about, both by the GCG representatives and the group’s ovarian cancer patient members. PARP inhibitors became an issue that the GCG

---

<sup>19</sup> Code, “Care, Concern, and Advocacy”, 5.

<sup>20</sup> My attention to palliative care is thanks to conversations I have had with my former postdoctoral mentor, Professor Vicky Singleton, about forms of end of life care, her work on Hospice care, and our collaboration around these issues. This collaboration has made me look differently at my fieldwork with the GCG, and have encouraged me to attend to how palliative care can “generatively unsettle” some of the more predominant practices of the GCG, focused on biomedical treatments.

<sup>21</sup> See for example, Kerr, Anne, Julia Swallow, Choon Key Chekar, and Sarah Cunningham-Burley. “Genomic Research and the Cancer Clinic: Uncertainty and Expectations in Professional Accounts.” *New Genetics and Society* 38, no. 2 (2019).

<sup>22</sup> Pols, “Knowing Patients.”

invested intense attention, hope and engagement into. For example, at a board meeting in August 2019, Karin told the rest of the group that she and one of the other board members, Alzena, have had a telephone meeting with the responsible governmental agency, The Dental and Pharmaceutical Benefits Agency. In an agitated tone, she told us that she had said to them “you know that we’re talking about women between life and death, why does not [an approval] arrive?”. She also said that Caroline had been to the agency, bringing photos of her mother with her. The aim was, Karin said, to show the agency that “it’s real people” affected by the slow approval of the subsidisation to non-BRCA mutation carriers (as many new cancer drugs PARP inhibitors are way too expensive for patients to pay for without subsidization). Karin also emphasised that PARP inhibitors are “the best thing that has happened for a long time for ovarian cancer patients”. Similarly, during a meeting in October 2019, Karin called PARP inhibitors “the new revolution for ovarian cancer patients”. “PARP inhibitors will, you know, revolutionise the treatment of ovarian cancer now when they are not only provided to BRCA carriers”, she said.

At the meeting, it was also agreed to include PARP inhibitors as a theme at the group’s yearly evening seminar in the Spring of 2020 (a seminar targeting patients, scientists and healthcare professionals). Karin emphasised that since PARP inhibitors are important for many patients, she thinks that these pharmaceuticals should be included at the seminar. As the group often does, she related to the GCG’s Facebook support group when saying this. She said that PARP inhibitors are talked extensively about in the support group, and that the ovarian patients in the group have a lot of questions about what approval would mean for them. She highlighted that many patients wonder about how PARP inhibitors might change possibilities for survival and what the side-effects are. Therefore, that it is important that the GCG helps patients by, through the seminar, providing knowledge about what an approval of PARP inhibitors would mean for them. At the meeting, through the focus on the Facebook support group, the topic of PARP inhibitors was not discussed as “in general” important for ovarian cancer patients; the discussion was situated to what the group had learned from their Facebook group, and from ovarian cancer patients. In this sense, the inclusion of PARP inhibitors at the evening seminar can be understood as an advocacy practice that

starts from the fact that patients live with cancer, and from patients' embodied realities.

In the face of life-threatening disease (“women between life and death” as Karin said at the above meeting), it is fully understandable that high expectations are invested in new treatments such as PARP inhibitors, and that such drugs are intensely cared about by advocates. Given that ovarian cancer is most often detected in advanced stages, it is even more so. But at the same time, since care is a selective mode of attention, this care for PARP inhibitors might also marginalise or exclude other potentially important matters. During my fieldwork, I noticed that the attention to PARP inhibitors as “the new revolution” have tended to marginalise existing scientific uncertainties.<sup>23</sup> While PARP inhibitors, according to the current evidence-base, may prolong an ovarian cancer patient's life with approximately up to 18 months, clinical trials have not been able to provide clear evidence for increased survival.<sup>24</sup> During the meetings in the fall of 2019 that I attended, such scientific uncertainties and specificities were not attended to.

However, saying that scientific uncertainties and specificities get marginalised or excluded is not the same as saying that it is problematic that PARP inhibitors are focused on, or that patient advocates should not try to speed up patients' access to them. The GCG representatives' attention to the support group is important in this regard, as it makes present a practice that is attuned to patients' embodied realities. The decision to focus on PARP inhibitors was not made simply because of a vision of these pharmaceuticals as the new ovarian cancer revolution, but because the GCG representatives had learned from patients that *they* care about PARP inhibitors. This, I argue, makes visible the problematics of reducing PARP inhibitors to only concerns about how advocacy practices focused on biomedicine risk, marginalising other things. As Karin said at the meeting, PARP inhibitors *do* concern “women between life and death”. Therefore, attuning patient advocacy

---

<sup>23</sup> Coleman, Shawnta, Prema P. Peethambaram, and Aminah Jatoui. “Consumer Beware: A Systematic Assessment of Potential Bias in the Lay Electronic Media to Examine the Portrayal of ‘PARP’ Inhibitors for Cancer Treatment.” *Journal of Cancer Education* 26, no. 3 (2011).

<sup>24</sup> National Ovarian Cancer Guidelines, last modified May 20, 2020, <https://www.cancercentrum.se/syd/cancerdiagnoser/gynekologi/aggstock/vardprogram/>.

to embodied realities of ovarian cancer might also mean to attune to new cancer drugs such as PARP inhibitors, while at the same keeping in mind the risks of reducing uncertainties and enacting unrealistic expectations. Holding together the high-scale politics of biomedicine and the embodied realities of women such as Caroline, her mother and the ovarian cancer patients in the support group, I argue it is important to understand the GCG's practices around PARP inhibitors, and to perform a care-full critique of cancer advocacy practices such as these.

### **Living and dying well**

In the last section I focused in on the GCG's advocacy concerning new biomedical treatments through the case of PARP inhibitors, to show how the GCG's practices entangle biomedicine and embodied realities of cancer. In doing so, I followed a common route in STS research where biomedicine is given priority in analyses of patient activism<sup>25</sup>, and I have, myself, excluded other important parts of the GCG's advocacy practices. STS scholar Ingunn Moser argues that there is a "science centrism" in STS, and that this "contributes to the dominance of science and biomedicine by granting these analytical privileges".<sup>26</sup> As a result, she continues, "alternative modes of acting, for instance in care, are disarticulated and made absent".<sup>27</sup>

While I have excluded this so far from my analysis, Moser's critique is not foreign to the GCG. Indeed, the GCG representatives have discussed similar matters among each other. During the last couple of years, they have also started to focus more on practices of living well with gynaecological cancer, both by influencing policy-actors to improve, for example, rehabilitation and palliative care practices, and by communicating knowledge about such matters to patients and their relatives.

As an example, during the GCG's evening seminar in April 2019, the group included a presentation on palliative care, this with the aim to provide patients knowledge about what palliative care is, and what

---

<sup>25</sup> For example, Callon, Michel, and Vololona Rabeharisoa. "Research 'in the Wild' and the Shaping of New Social Identities." *Technology in Society* 25, no. 2 (2003); Panofsky, Aaron. "Generating Sociability to Drive Science: Patient Advocacy Organizations and Genetics Research." *Social Studies of Science* 41, no. 1 (2011).

<sup>26</sup> Moser, "Dementia and the Limits to Life", 704.

<sup>27</sup> Moser, "Dementia and the Limits to Life", 704.

they as patients can expect from it. As was discussed during planning meetings prior to the seminar, the GCG had learned from, for example, their Facebook support group that many patients do not know that much about what palliative care means, and that many are afraid that they will be in much pain during the terminal phase of their disease. For example, at a planning meeting in October 2018, the board member Gunilla, a chronic ovarian cancer patient herself, emphasised that it is crucial that the GCG provides patients a space to learn about palliative care, this as it can help them in their struggle with coming to terms with their own imminent death. She stressed that she knows this from her own disease but also from the Facebook support group, in which she is an active member. Before the presentation at the seminar in April 2019, Gunilla, who was the moderator for the evening, said that “I can be sure that I will die from this cancer”, and that she therefore wants to know about palliative care and how it can help her. During the presentation a palliative care nurse explained that it is important to be “responsive” and “take in” what every patient needs. It is about creating relations to the patients and about learning from those relations; as patients are different, palliative care needs to be attuned to such differences. “What we want is to create quality of life”, she said. After the seminar, Gunilla emphasised that the GCG thinks it is important to raise these more sensitive issues, which palliative care serves as an example of.

The GCG’s practices around palliative care make visible another form of patient advocacy than the one focused on the speeding up of new biomedical treatments. It is a form of practice attuned to creating liveable lives in the presence of imminent death as an embodied reality for many cancer patients. Moreover, which I here have exemplified through the evening seminar presentation, it is a practice that enacts care as a matter of being responsive to, and holds on to, differences and relationality. This fleshes out a form of care that “remains open-ended and responsive: one does not know in advance where this attention will lead”.<sup>28</sup>

Moser argues that by primarily attending to “cutting-edge science and technology” there is a risk that STS analyses “run the risk of colluding and contributing to making present and more real very

---

<sup>28</sup> Martin, Myers and Viseu, “The Politics of Care in Technoscience”, 630.

particular versions of reality; of assuming that these are more powerful and make their way into, impose themselves upon, and order other locations and practices”.<sup>29</sup> As a consequence, other worlds, risk becoming weaker and less real. In this section, I have responded to this critique by highlighting the GCG’s focus on palliative care. This has made present an advocacy practice that is not centred on biomedical solutions, but on providing knowledge to patients with chronic cancer, knowledge that allows them to think about care as an open-ended practice attuned to the specificity of each care relation, and that hopefully can help them in their struggles with their imminent death. Through this focus on palliative care I have also attended to how Gunilla, as a chronic ovarian cancer patient herself, cares about questions of palliative care, and how she is committed to allowing cancer patients space and time to come to terms with their own death. Learning from Moser<sup>30</sup>, if we as STS researchers take for granted that biomedicine is what cancer patient advocates really care about, then other cancer worlds, indeed, risk being marginalised and devalued.

### **Concluding thoughts**

In this paper I have explored different modes of attending to gynaecological cancer patient advocacy practice as a way of responding to the question of “how to care for our accounts?”.<sup>31</sup> I started with advocate, Caroline, to explore how her advocacy can be understood as an entanglement of care and knowing, and of embodied cancer experience and politics of biomedicine and cancer (in)visibility. I then adopted another mode of attention, more in line with an STS frequently used approach of “following the object”<sup>32</sup> (here, PARP inhibitors), to exemplify how also the GCG’s practices around biomedicine are entangled with embodied realities of cancer. Finally, I attended to the example of the GCG’s advocacy around palliative care to trouble my own, and in STS, frequent tendency to prioritise biomedicine.

Through these modes of attention, I have highlighted what could be called some of the “affective tensions” between the personal and the

---

<sup>29</sup> Moser, “Dementia and the Limits to Life”, 707.

<sup>30</sup> Moser, “Dementia and the Limits to Life”.

<sup>31</sup> Jerak-Zuiderent, “How to Care for our Accounts?”.

<sup>32</sup> For example, Latour, Bruno. *Science in Action: How to Follow Scientists and Engineers through Society*. Boston: Harvard University Press, 1987.

abstract (between life and death) involved in cancer activism. In focusing on such affective attentions, I have been thinking with the metaphor of scaling – scaling up and scaling down – as a sensitising lens to zoom in and out between the personal, embodied, affective, and the high-scale cancer politics this is entangled with. I have done so to highlight the politics the GCG’s practices, and to discuss how I as the researcher might re-tell the stories and practices I have learnt through my fieldwork in a way that “stays true” to the GCG representatives while at the same time making links to larger political relations and concerns. This way of doing care-full critique is perhaps for me, most importantly, to try to think through what it might mean to be in ethical relation with others – with my participants and with what Caroline called “the cancer world” – and how to care for “care” in a way that holds on to the tensions of entangled cancer relations.

# Feminist Para-Ethnographies: A Proposition for a ‘Critical Friendship’ Between Embodied Experiences and Microbiome Science

Andrea Núñez Casal

*For more than a decade, I have been aware of colonies of Escherichia coli (E.coli) populating my urinary tract, a bacterium found in mammals and birds, plants, and soil. My bladder and kidneys were in a constant circuit of pain–remission for several weeks for years. Countless prescriptions of nitrofurantoin, trimethoprim, norfloxacin, ciprofloxacin (i.e. antibiotics), paracetamol, naproxen, ibuprofen (UK), buscapina (Spain), Uro-vaxon (found and bought in Brazil), Uronid (Spain). Ferrol (Spain): three days in the hospital. London, UK: scan done, three cystoscopies cancelled. Doctors told me that my recurrent urinary tract infection (UTI) was probably a consequence of a weakened immune system. This came at a time when I did not yet know the meteoric emergence of a new scientific area of biomedical research: the human microbiome.*

*Contrary to my recurrent UTIs, my pregnancy came at a time when my research on human microbiome science was relatively advanced. By that time, I had gathered all the data and I was in the process of analysis and writing up. This period was interesting from an intellectual viewpoint. On the one hand, in human microbiome studies, pregnant and breastfeeding female bodies are biomedically valuable due to the major shifts in microbial communities in both the woman’s and the infant’s body. On the other hand, pregnancy carries an increased risk of UTI, especially for those women with (unexplained) recurrent UTIs. According to classical immunological theory, in pregnancy, the immune system weakens in order to tolerate the fetus. And this is the reason why infections are more common. What might be a minor and very mild infection in non-pregnant women might become serious and with long-term consequences for the pregnant woman and the fetus. Prenatal infections are associated with preterm delivery, stillbirth, and sepsis, to name a few.*



*Importantly, there is an unknown burden of antimicrobial resistance (AMR) on women's health, especially in poorer countries.*

‘All matters of fact require, in order to exist, a bewildering variety of matters of concern.’<sup>1</sup> ‘Matters of fact’ refers to scientific hypotheses, theories and experiments posed as ‘objective’ and represented by the ‘hard sciences’. ‘Matters of concern’, on the other hand, refers to interpretations, beliefs, opinions and speculations regarded as subjective and represented by the humanities and social sciences. In this piece, I ask: How to co-generate a ‘critical friendship’<sup>2</sup> between ‘matters of fact’ and ‘matters of concern’? In response to this question, I introduce a theoretical proposition and methodological tools aimed at knowledge-practices of co-existence, care and decoloniality, what I call ‘feminist para-ethnographies’. This piece draws on my embodied experiences of urinary tract infections (UTIs), (mostly) feminist literature on scientific knowledge production<sup>3</sup> and some vignettes from my ethnographic fieldwork on the vertical transmission of microbes. I argue that ‘feminist para-ethnographies’ complement what ‘evidence-based biomedicine’ fails to register and see through the realisation of what Denise Riley calls ‘socialised biology’<sup>4</sup>, which refers to biology ‘lived within particular lives.’<sup>5</sup>

My proposition of ‘feminist para-ethnographies’ is a reformulation of Holmes and Marcus’s concept of the para-ethnographic – ‘a way of dealing with contradictions, exceptions, and

---

<sup>1</sup> Bruno Latour, ‘Why Has Critique Run out of Steam? From Matters of Fact to Matters of Concern’, *Critical Inquiry* 30, no. 2 (January 2004): 247.

<sup>2</sup> Nikolas Rose, ‘The Human Sciences in a Biological Age’, *Theory, Culture & Society* 30, no. 1 (1 January 2013): 3–34.

<sup>3</sup> Vinciane Despret, ‘The Body We Care for: Figures of Anthro-Zoo-Genesis’, *Body & Society* 10, no. 2–3 (1 June 2004): 111–34; Latour, ‘Why Has Critique Run out of Steam?’; Isabelle Stengers, *The Invention of Modern Science* (Minneapolis: University of Minnesota Press, 2000); Isabelle Stengers, *Another Science Is Possible: A Manifesto for Slow Science*, trans. Stephen Muecke, 1 edition (Cambridge; Medford, MA: Polity, 2018).

<sup>4</sup> Denise Riley, *War In The Nursery: Theories of the Child and Mother* (London: Virago, 1983).

<sup>5</sup> Riley, *War In The Nursery*, 40.

facts that are fugitive’<sup>6</sup> – as a feminist intersectional and situated practice that entangles the researcher’s embodied experiences with ‘fugitive’ qualitative data in technoscientific claims and quantitative (microbiome) research. This dimension of feminist para-ethnographies takes up Riley’s ‘socialised biology’ ethos of accounting for how ‘biology is lived out’ in all its embodied and, crucially, political sense.<sup>7</sup> Its core is based on the socialisation of care and the delivery of health justice through the transformation of silenced and private embodied experiences into shared, socialised, experiences.<sup>8</sup>

Feminist para-ethnographies are a method of registration, documentation and interpretation of embodied experiences of health and disease as part of medical diagnostic and therapeutic data, offering a de-medicalised approach. As Anderson and Mackay sustain, in relation to autoimmunity, (embodied) biographies are an indispensable part of the efficacy of more conventional medical treatments.<sup>9</sup> My proposition has very much to do with the ‘ethnographic turn’ Mol and Law call for as part of a ‘multi-voiced form of investigative story telling.’<sup>10</sup> This requires the research design of tools in order to record, document, and provide situated accounts of embodied biological experience or ‘socialised biology.’<sup>11</sup> In doing so, our individual and collective knowledges, practices, and embodied experiences as sentient beings – as sufferers but also as researchers, clinicians, midwives, microbiologists, immunologists, etc – are crucial.<sup>12</sup>

---

<sup>6</sup> Douglas R. Holmes and George E. Marcus, ‘Collaboration Today and the Re-Imagination of the Classic Scene of Fieldwork Encounter’, *Collaborative Anthropologies* 1, no. 1 (2008): 596.

<sup>7</sup> Riley, *War In The Nursery*, 30.

<sup>8</sup> Andrea Núñez Casal, ‘The Microbiomisation of Social Categories of Difference: An Interdisciplinary Critical Science Study of the Human Microbiome as the Re-Enactment of the Immune Self’ (doctoral, Goldsmiths, University of London, 2019).

<sup>9</sup> Warwick Anderson and Ian R. Mackay, *Intolerant Bodies: A Short History of Autoimmunity*, 1st edition (Baltimore: Johns Hopkins University Press, 2014).

<sup>10</sup> Annemarie Mol and John Law, ‘Embodied Action, Enacted Bodies: The Example of Hypoglycaemia’, *Body & Society* 10, no. 2–3 (June 2004): 59.

<sup>11</sup> Riley, *War In The Nursery*.

<sup>12</sup> Andrea Núñez Casal, ‘It Begins with Us: On Why Our Embodied Experiences Matter in the Dis/appearance of Worlds’, *EASST Review* 40, no.1 (March 2021).

### **Introducing ‘Facts-Concerns’: Pasteurianism vs Post-Pasteurianism in the Microbiology of Reproduction**

The immunitary role and antimicrobial quality of the placenta have been a central dogma in gynaecology and obstetrics. The ‘sterile womb paradigm’ or, in other words, the placenta as the physical-reproductive barrier impeding contact between the fetus and microbes, has been debated for about 150 years, reaching scientific consensus in the second half of the twentieth century.<sup>13</sup> From this perspective, the immune system weakens in pregnancy to ‘tolerate’ the fetus, making pregnant women more vulnerable to infections. This discourse has dictated much of the public health campaigns and advice targeted at pregnant women. For example, contact with cat faeces during pregnancy might be dangerous because of the *Toxoplasma gondii* parasite. This parasite is able to cross the placenta and infect the fetus. The consequences can be lasting and include mental and physical developmental ‘delays’. Pregnant women are also advised to avoid unpasteurised dairy products<sup>14</sup>, soft cheeses and patés, and any undercooked food to prevent listeriosis. Listeriosis is an infection caused by the bacterium *Listeria monocytogenes*, which ‘lives’ in vegetables, butter, and meat.

The exposure to the bacterium in uterus can lead to miscarriage, premature birth, or stillbirth. While these two examples are some of the more serious and dramatic cases of infection in pregnancy, the biomedical discourse that permeates public opinion (via public health campaigns) is that microbes, more generally, are particularly dangerous in pregnancy. Even in cases in which there is little or no evidence on the effect of viruses and bacteria on pregnancy and fetuses, like the case of influenza, for example, the recommendations are to get the flu jab or to avoid close contact with sick people.

New evidence in human microbiome research using molecular techniques, however, suggests that the womb, the placenta, and the umbilical cord are not microbe free.<sup>15</sup> This new theory, known as the

---

<sup>13</sup> Maria Elisa Perez-Muñoz et al., ‘A Critical Assessment of the “Sterile Womb” and “in Utero Colonization” Hypotheses: Implications for Research on the Pioneer Infant Microbiome’, *Microbiome* 5, no. 1 (28 April 2017): 2.

<sup>14</sup> Heather Paxson, ‘Post-Pasteurian Cultures: The Microbiopolitics of Raw-Milk Cheese in the United States’, *Cultural Anthropology* 23, no. 1 (2008): 15–47.

<sup>15</sup> Lisa J. Funkhouser and Seth R. Bordenstein, ‘Mom Knows Best: The Universality of Maternal Microbial Transmission’, *PLoS Biology* 11, no. 8 (2013):

‘in utero colonisation’ hypothesis, proposes that the placenta harbours its microbiome.<sup>16</sup> Likewise, fetuses acquire microbial communities not at birth, during the passage from the birth canal to ‘world’, but rather microbial acquisition and exposure occurs prenatally, in utero.

### **‘Interdisciplinary Solutions’ to Biome Depletion**

One of the aspects that attracted me to documenting and following human microbiome science was its marked interdisciplinary ethos. My ethnographic fieldwork of ‘indigenous’ microbes and the microbiology of modes of delivery at birth were both formed of interdisciplinary teams of physicians, microbial ecologists, architects, and bioinformaticians. Both studies examined the influence of ‘modern practices’, with a special focus on antibiotics, cesarean sections and processed foods. With regards to the microbiology of reproduction, one of my ‘epistemic partners’<sup>17</sup> expressed that ‘C-section, precludes the new-born from obtaining the original inoculum, and further impacts ... exerted via bottle feeding, antibiotics, processed foods, etc. ... disrupt the microbiome transmission and sustainability’.<sup>18</sup>

To compensate for the lack of microbial exposure in babies born via caesarean section, this team of scientists pioneered a (markedly post-Pasteurian) technique of ‘microbial restoration’ (or re-embodiment) known as ‘vaginal seeding’. This technique consists of the relatively simple practice of inoculating neonates with maternal vaginal flora immediately following a caesarean section delivery. Gauze swabs are placed in the mother’s vagina. After the caesarean birth, the gauze is rubbed onto the baby’s skin. The idea is to mimic the vertical transmission of microbes in babies born by vaginal delivery. In this way,

---

e1001631, <https://doi.org/10.1371/journal.pbio.1001631>; Perez-Muñoz et al., ‘A Critical Assessment of the “Sterile Womb” and “in Utero Colonization” Hypotheses’.

<sup>16</sup> Perez-Muñoz et al., ‘A Critical Assessment of the “Sterile Womb” and “in Utero Colonization” Hypotheses’.

<sup>17</sup> Holmes and Marcus, ‘Collaboration Today and the Re-Imagination of the Classic Scene of Fieldwork Encounter’.

<sup>18</sup> M G Dominguez-Bello, ‘Genomics and Global Health in the Context of Transculturation.’ (Infectious Disease Genomics and Global Health, Hinxton, United Kingdom, October 2013).

microbiome scientists believe that immunity response to inflammatory diseases, asthma and allergies are boosted.<sup>19</sup>

In spite of the optimism, the open post-Pasteurianism of vaginal seeding makes it a controversial method of microbial restoration. There is no scientific consensus yet, mainly because of the lack of clinical trials. A Danish research group on the issue reported that the main risk is serious infection in newborns<sup>20</sup>. Overall, the current medical recommendation advises against it.<sup>21</sup>

What this example of an interdisciplinary solution to biome restoration shows is that the immunitary logic of Pasteurianism (i.e. fear of microbes, fear of infection) dominates not only clinical practice but the possibilities of research innovation through, for instance, more clinical trials on a (post-Pasteurian) technique such as ‘vaginal seeding’. But vaginal seeding is also interesting because it connects to care as a sustainable method of biome restoration in healthcare,<sup>22</sup> of ‘staying with the trouble’.<sup>23</sup> In fact, it can be framed as ‘social medicine’; as a universal and public microbiome initiative.

It is important to point out that microbiome science is sustained through (neocolonial) practices of bioprospecting the microbial diversity from non-Western(ised) communities, societies, and locales<sup>24</sup>. This crucial aspect of microbiome science would need further space for elaboration, but I would like to remark on the fact that ‘microbiome’ therapeutics (including the aforementioned methods or ‘solutions’) are only applicable to medical conditions affecting rich nations (i.e. inflammatory, autoimmune, and metabolic diseases)<sup>25</sup>. My concern is:

<sup>19</sup> M G Dominguez-Bello, Personal Communication, 28 January 2014.

<sup>20</sup> ‘C-Section Mums Warned about Dangers of “Vaginal Seeding”’, nhs.uk, 23 August 2017, <https://www.nhs.uk/news/pregnancy-and-child/c-section-mums-warned-about-dangers-vaginal-seeding/>.

<sup>21</sup> T. Haahr et al., ‘Vaginal Seeding or Vaginal Microbial Transfer from the Mother to the Caesarean-Born Neonate: A Commentary Regarding Clinical Management’, *BJOG: An International Journal of Obstetrics and Gynaecology* 125, no. 5 (2018): 533–36.

<sup>22</sup> Rodney R. Dietert and Janice M. Dietert, ‘The Microbiome and Sustainable Healthcare’, in *Healthcare*, vol. 3 (Multidisciplinary Digital Publishing Institute, 2015), 100–129.

<sup>23</sup> Donna J. Haraway, *Staying With the Trouble: Making Kin in the Chthulucene* (Durham: Duke University Press, 2016).

<sup>24</sup> Núñez Casal, ‘The Microbiomisation of Social Categories of Difference’.

<sup>25</sup> Núñez Casal, ‘The Microbiomisation of Social Categories of Difference’.

how to secure the social contract (especially for the disadvantaged) of this kind of microbiome initiatives? Where is, or what is the role of, the social? Who would bring the social agenda, particularly in the sense of inequalities in health and disease, to the forefront of these microbiome initiatives?

Beyond Ethical and Socio-Legal Implications (ELSI) frameworks, the social can no longer be elicited from the biological in so-called ‘interdisciplinarity’ microbiome research. The main question I ask in this piece is how to foster a ‘critical friendship’,<sup>26</sup> but a ‘critical friendship’ able to generate assemblages between ‘matters of fact’ and ‘matters of concern’<sup>27</sup>. What is important are alliances between the sciences and the social sciences and humanities in which the social is, first of all, included; second, re-valued; third, listened to.

I would like now to turn to how the social sciences approach the ‘factualities’ around the microbiology of reproduction. In doing so, I examine my postpartum experience as a ‘matter of concern’ through the lens of feminist literature on reproduction, mainly drawing on the work of feminist anthropologist Emily Martin.<sup>28</sup>

### ‘Producing’ Humans

*It is 3 September 2016. I am in labour. I arrived at the University College London Hospital (UCLH) maternity department in the afternoon, after waiting at home with mild contractions for several hours. It is Sunday and the maternity unit seems very quiet, with very few staff and patients. I am quickly moved to the birth centre, which is located on the fifth floor of the hospital. I can barely walk. The warm voice and hands of the midwife on rota comforted me while in the elevator. We enter the birth centre. My room looks like a spartan hotel room, although the big bathtub (for a waterbirth) makes a difference. A midwife comes every fifteen minutes for fetal heart rate monitoring. The transducer is placed against my abdomen to hear the fetus’s heartbeat. This is the third time the midwife comes to perform the auscultation. Complications started. I realise that I am bleeding heavily. Most worrying, she cannot detect the fetus’s heartbeat. We are rushed to the labour ward.*

---

<sup>26</sup> Rose, ‘The Human Sciences in a Biological Age’.

<sup>27</sup> Despret, ‘The Body We Care For’; Latour, ‘Why Has Critique Run out of Steam?’; Stengers, *Another Science Is Possible*.

<sup>28</sup> Emily Martin, *The Woman in the Body: A Cultural Analysis of Reproduction: With a New Introduction*, 1st ed. (Boston: Beacon Press, 2001).

*At the ward, my midwife nervously asks me to wear a belt which monitors and records contractions and fetal heartbeat electronically. She insists on antibiotic administration. I reject it. I do not have masochistic tendencies, but I have not taken any medications during all the pregnancy. I have been very careful and done lots of research on how to prevent UTI and other common illnesses in pregnancy.*

*I am in labour, which is not a medical condition. I am not a patient because I am not sick. But my wish is not translatable to what Annemarie Mol (2008) describes as the 'logic of choice', the dominant healthcare approach in richer nations based on (Enlightened) rationalism and neoliberal individualism (i.e. patients as consumers), simply because I am not a patient. And things are starting to go wrong. Unwillingly, I am becoming a patient.*

This idea of the pregnant woman as being untrustworthy in her decisions or feelings during labour links with what feminist anthropologist Emily Martin argues in *The Woman in the Body* (2001). She insightfully shows that biomedicine does not capture (or erase, I would say) women's embodied experience of menstruation, birth, and menopause. In doing so, science creates, recreates, and reproduces binarisms. As she writes:

Usually we do not hear the story, we only hear the 'facts', and this is part of what makes science so powerful. But women - whose bodily experience is denigrated and demolished by models implying failed production, waste, decay, and breakdown have it literally within them to confront the story science tells with another story, based in their own experience. ... When women derive their view of experience from their bodily processes as they occur in society, they are not saying 'back to nature' in any way. They are saying on to another kind of culture, one in which our current rigid separations and oppositions are not present.<sup>29</sup>

Embodied experiences advance other kinds of cultures. A culture that contrasts with the dominant ideology of evidence-based biomedicine,

---

<sup>29</sup> Martin, 197, 200.

rooted in the confrontation between objectivity and subjectivity. In binarism. This is to say that the study of women’s embodied experiences of reproductive processes not only translate into health disparities but in possibilities (e.g. resistance). It is in this sense that embodied experiences can be read through the lens of Federici’s figures of *Caliban and the Witch* (2004)<sup>30</sup>. Caliban, the ‘anti-colonial rebel’, is a symbol of ‘the proletarian body as a terrain and instrument of resistance to the logic of capitalism’<sup>31</sup>. The witch embodies ‘a world of female subjects that capitalism had to destroy: the heretic, the healer, the disobedient wife, the women who dared to live alone, the obeah woman who poisoned the master’s food and inspired the slaves to revolt’.<sup>32</sup>

In a different context, feminist writer and poet Denise Riley argues that British developmental psychology relied on unemployed mothers<sup>33</sup>. This has to do with the fact that developmental psychology understands ‘socialisation’ (through the mother) as a ‘linear process’ and the social self as a ‘cumulative progress’<sup>34</sup>. This is sustained in the belief that babies are born closer to biology and then get ‘more and more social’ through time.<sup>35</sup> Riley refers to this idea as the ‘priority of the biological’, a precondition for the opposition between the biological and the social, the individual and society, nature and culture or, in Latourian terms, between ‘matters of fact’ and ‘matters of concern’. For Riley, instead, ‘the individual is always already social, always there’<sup>36</sup>, and she proposes ‘socialised biology’ as a concept to undo binarist thinking.

Riley’s concept is key for my proposition of feminist para-ethnographies as material-semiotic devices to register ‘socialised biology’. Embodied experiences are in fact a form of resistance against the medicalisation of reproduction, against the control and domination of women’s bodies. Yet my argument is that, although this type of analysis offers valuable critical reflection, it has an important limitation: this kind of critique does not build alliances that assemblage and

---

<sup>30</sup> Silvia Beatriz Federici, *Caliban and the Witch*, 2., rev. ed (New York, NY: Autonomedia, 2014).

<sup>31</sup> Federici, *Caliban and the Witch*, 11.

<sup>32</sup> Federici, *Caliban and the Witch*, 11.

<sup>33</sup> Riley, *War In The Nursery*.

<sup>34</sup> Riley, *War In The Nursery*, 33.

<sup>35</sup> Riley, *War In The Nursery*, 33.

<sup>36</sup> Riley, *War In The Nursery*, 33.



gather.<sup>37</sup> Similarly, Isabelle Stengers has recently expressed her concerns regarding the humanities' 'self-proclaimed privileged' critical standpoint.<sup>38</sup>

### **Becoming Available**

In building alliances and a 'critical friendship'<sup>39</sup> between (my) embodied experiences and microbiome science, between 'matters of fact' and 'matters of concern' more broadly, feminist philosopher and animal studies scholar Vincianne Despret's concept of 'becoming available' is an extremely insightful and valuable notion through which to explore how 'human and non-human bodies become more sensitive to each other'.<sup>40</sup> For Despret, the definition of beliefs and expectations in terms of 'availability' help to 'overcome the great dividing-up that results from the "will to make science"'<sup>41</sup>. By focusing on availability, both the subject and the world are 'active and both are transformed by the availability of the other. Both are articulated by what the other 'makes him/her make'<sup>42</sup>. Furthermore, Despret's availability is fundamentally a caring practice. As she puts it:

The experimenter, far from keeping himself his body, he involves his knowledge, his responsibility and his future. The practice of knowing has become a practice of caring. And because he cares for his young goose, he learns what, in a world inhabited by humans and geese, may produce relations.<sup>43</sup>

I would like to illustrate Despret's proposition of availability with a short vignette of how I became available to new relations and new identities with microbes.

*Over time, I noticed a bodily pattern: A few days before suffering a UTI, a herpes simplex virus (HSV-1), physically manifested as a cold sore on*

---

<sup>37</sup> Latour, 'Why Has Critique Run out of Steam?'

<sup>38</sup> Stengers, *Another Science Is Possible*, 126.

<sup>39</sup> Rose, 'The Human Sciences in a Biological Age'.

<sup>40</sup> Despret, 'The Body We Care For', 114.

<sup>41</sup> Despret, 'The Body We Care For', 125.

<sup>42</sup> Despret, 'The Body We Care For', 125.

<sup>43</sup> Despret, 'The Body We Care For', 130.

*either my upper or lower lip. I interpreted this biological occurrence not as an isolated fact without relation to other body parts (i.e. bladder, kidneys) but as a ‘message’ or ‘sign’ delivered by the virus. I wondered: was there a relation between these two microbial communities (i.e. E. coli and herpes simplex) harboured within my body?*

*Herpes simplex virus is a life-long infection. Its persistent form is in a latent state in the neural ganglia, a group of nerve-cells bodies of the nervous system. Periods of reactivation or viral replication are characterised by periodic recurrence or outbreaks, which produce cold sores. I believed that the herpes virus in its activated form through the appearance of a cold sore had a meaning: the beginning of a UTI. I was also certain that both infections were closely related to my impaired immunity in periods of either emotional and/or physical stress.*

The singularity of my experiences, I argue, allows experimentation and attunement in microbe–human relations beyond evidence-based biomedicine and the rigid precepts of scientific objectivity. My ‘becoming available’ to new (non-pathogenic) relations, to different ways of becoming-with microbes, is not just mediated by my decade-long embodied experiences as a ‘patient’ or ‘sufferer’ of UTIs (what belongs to ‘matters of concern’) but also by my knowledges-practices as a researcher (what belongs to ‘matters of fact’). This is to say that both, my embodied experiences (concerns) and my academic practice (facts?), are indissociable (facts-concerns) parts of ‘becoming available’ to microbes. This, in turn, brings up issues related to the situatedness of social scientists, as to how researchers’ embodied experiences participate in knowledge production.<sup>44</sup>

Likewise, in devising how ‘human and non-human bodies become more sensitive to each other’<sup>45</sup>, I supplement Despret’s notion of ‘availability’ with what philosopher of science Isabelle Stengers calls ‘connoisseurs’<sup>46</sup>. Connoisseurs are ‘agents of resistance against a scientific knowledge that pretends it has general authority; they partake

---

<sup>44</sup> See Núñez Casal, ‘It Begins with Us’.

<sup>45</sup> Despret, ‘The Body We Care For’, 114.

<sup>46</sup> Stengers, *Another Science Is Possible*.

in the production of what Donna Haraway calls ‘situated knowledges’<sup>47</sup>. As she continues:

Connoisseurs are not advocates of ‘alternative’ knowledge, looking for professional recognition. But their interest in the knowledges produced by scientists is different from the interest of the producers of these knowledges. It is for this reason that they can appreciate the originality or the relevance of an idea but also pay attention to questions or possibilities that were not taken into account in its production, but that might become important in other circumstances.<sup>48</sup>

Bringing together Despret’s ‘availability’ and Stengers’ ‘connoisseurs’ demands to reconfigure the role of connoisseurs through the inclusion of embodied experiences. I suggest that embodied experiences as part of connoisseurs’ repertoire make ‘available’<sup>49</sup> new subjectivities and identities, new ways of knowing and making knowledge, and crucially, new forms of (health)care (e.g. medical diagnosis, therapeutic data, and treatments).

### **Feminist Para-ethnographies**

Feminist para-ethnographies aim at changing perspectives and methodologies in human microbiome science through the re-evaluation of embodied experiences of health and disease. María Puig de la Bellacasa argues that soil as a living multispecies community requires different temporalities to those based on innovation, productivism, and profitability<sup>50</sup>. Likewise, feminist para-ethnographies call for a different way of making science. Here Isabelle Stengers’ recent ‘slow science’ manifesto provides a helpful basis on which to build alternative knowledge practices of care and decoloniality based on alliances, therefore moving beyond the constraints of ‘interdisciplinary’ and ‘objective’ frameworks. But care as a feminist proposition in the

---

<sup>47</sup> Stengers, *Another Science Is Possible*, 9.

<sup>48</sup> Stengers, *Another Science Is Possible*, 9.

<sup>49</sup> Despret, ‘The Body We Care For’.

<sup>50</sup> Maria Puig de la Bellacasa, ‘Making Time for Soil: Technoscientific Futurity and the Pace of Care’, *Social Studies of Science* 45, no. 5 (1 October 2015): 691–716.

sciences<sup>51</sup> and critical science studies scholarship should not be confused with harmonious, idealised, and romantic visions of care that neglect the ‘troubles of interdependent existences’<sup>52</sup>. It is ‘by staying in the thick of things, by analyzing care’s non-innocent politics that our responses can be slowed down enough to make them more care-ful’.<sup>53</sup>

It is important to remark that the ‘interdisciplinarity’ of feminist para-ethnographies is not about generating ‘seamless knowledges and unified politics’ or ‘conceptual monocultures’<sup>54</sup>. It is not my purpose to erase the tensions, gaps, and discontinuities in the distinct ways of producing and enacting knowledges and practices in the sciences and the social sciences and humanities. In other words, feminist para-ethnographies do not try to ‘settle’ matters. Likewise, inspired by Wilson’s ‘gut feminism’, I would like to reanimate feminist theories ‘by an engagement with biology— particularly a phantastic biology and a biology of the periphery’<sup>55</sup>. However, unlike Wilson’s proposition, feminist para-ethnographies are socially driven. That is, over experimentation, feminist para-ethnographies privilege the co-generation of knowledges-practices of engaged research, of social justice. After all, ‘care connotes attention and worry for those who can be harmed by an assemblage but whose voices are less valued, as are their concerns and need for care.’<sup>56</sup>

It is in this sense that feminist para-ethnographies – the imbrication between microbes, embodiment and inequalities – as tools to listen to and revalue devaluated embodied experiences have acquired an unprecedented importance amid the current SARS CoV-2 pandemic. In the absence of appropriate (health)care, dietary changes along with supplements from various medical traditions (e.g. Traditional Chinese Medicine (TCM), Ayurveda, homeopathy) have become part of a ‘more

---

<sup>51</sup> H. Rose, *Love, Power and Knowledge: Towards a Feminist Transformation of the Sciences* (Bloomington, Ind: Indiana University Press, 1994).

<sup>52</sup> Maria Puig de la Bellacasa, “‘Nothing Comes without Its World’: Thinking with Care”, *The Sociological Review* 60, no. 2 (1 May 2012): 199.

<sup>53</sup> Aryn Martin, Natasha Myers, and Ana Viseu, “The Politics of Care in Technoscience”, *Social Studies of Science* 45, no. 5 (1 October 2015): 12.

<sup>54</sup> Elizabeth A. Wilson, *Gut Feminism* (Durham: Duke University Press Books, 2015), 171.

<sup>55</sup> Wilson, *Gut Feminism*, 171.

<sup>56</sup> Maria Puig de la Bellacasa, ‘Matters of Care in Technoscience: Assembling Neglected Things’, *Social Studies of Science* 41, no. 1 (1 February 2011): 92,

collaborative' and 'more caring' bioeconomies<sup>57</sup> for those populations experiencing long-lasting symptoms and relapses of Covid-19 in order to address their multiple vulnerabilities and inequalities (i.e. healthcare, employment and childcare in convalescence). Giving voice to persistent Covid-19 online communities, my project *The Witch and the Microbe*<sup>58</sup> uses 'feminist para-ethnographies' to document, analyse and interpret the embodied experiences of prolonged Covid-19 (~+60 days) on various digital networks. Together with these online communities, it co-develops a 'lived' archive of the resulting ad hoc remedies, dietary and bodily practices used to live with/recover from the lingering symptoms of the disease. Here, what I call 'microbiology multiple' brings microbes and people into the 'science of microbiology' instead of the opposite. It focuses on embodiment and collective action rather than on a more interpretative dimension of health and wellbeing with(out) microbes.<sup>59</sup>

### **Conclusion: Feminist Para-ethnographies, Resistance**

Capitalism occludes care, it invisibilises it. Capitalism naturalises care by situating it in the sphere of maternal love. Care, or 'unwaged reproductive labour' in Federici's terms, was a necessary precondition for the development of capitalism in Europe<sup>60</sup>. Recent feminist literature, however, confers a new meaning to care, situating it in the sphere of resistance. That is, care can also be understood as an anti-capitalist and decolonial practice. 'Understanding caring as something we do extends a vision of care as an ethically and politically charged practice, one that has been at the forefront of feminist concern with devalued labours [e.g. childcare, domestic work]'.<sup>61</sup>

---

<sup>57</sup> Vincenzo Pavone and Joanna Goven, eds., *Bioeconomies* (Cham, Switzerland: Springer International Publishing, 2017).

<sup>58</sup> "The Witch and the Microbe: Lingering Covid-19 Embodiments, Food cultures, and Microbial Science", accessed 7 July 2020, <https://www.microbesembodimentinequalities.com>.

<sup>59</sup> Stephen Hinchliffe et al., 'Healthy Publics: Enabling Cultures and Environments for Health', *Palgrave Communications* 4, no. 1(15 May 2018): 1–10.

<sup>60</sup> Federici, *Caliban and the Witch*.

<sup>61</sup> Puig de la Bellacasa, 'Matters of Care in Technoscience', 90.

In conclusion, in this piece I have developed Despret's notion of 'becoming available'<sup>62</sup> as a necessary precondition of feminist para-ethnographies. I have developed the proposition of feminist para-ethnographies as 'critical friendship' methods or tools<sup>63</sup> for 'connoisseurs'<sup>64</sup>; connoisseurs as 'mediums' or 'agents' through which to 'become available' and realise 'socialised biology', that is biology 'lived out by the individual in a social form...lived within particular lives'<sup>65</sup>. Feminist para-ethnographies as the realisation and materialisation of 'socialised biology' are a social justice proposition to restore biome depletion across social classes and groups in order to alleviate health disparities resulting from microbiome science. In feminist para-ethnographies, the de-medicalisation and socialisation of care are the principal elements of biome restoration. This involves the re-embodiment of microbes by revaluing and de-individualising embodied experiences, turning them into shared bodily experiences (i.e. socialised biology). In this way, feminist para-ethnographies offer a window of opportunity to remodel the individualistic rhetoric and 'immuno-logics' of microbiome science<sup>66</sup>.

---

<sup>62</sup> Despret, 'The Body We Care For'; Vinciane Despret and Brett Buchanan, *What Would Animals Say If We Asked the Right Questions?* (Minneapolis: University of Minnesota Press, 2016).

<sup>63</sup> Rose, 'The Human Sciences in a Biological Age'.

<sup>64</sup> Stengers, *Another Science Is Possible*.

<sup>65</sup> Riley, *War In The Nursery*, 43.

<sup>66</sup> Núñez Casal, 'The Microbiomisation of Social Categories of Difference'.

# Choreography of Care

Keely Macarow

This is your hand, these are my hands, this is the world,  
which is round but not flat and has more colors  
than we can see.

It begins, it has an end,  
this is what you will  
come back to, this is your hand

- Margaret Atwood, extract from *You Begin*, 1978

Two women met in a lobby. One swayed from side to side, moved her feet and gestured with one hand as she spoke. A man also walked into the lobby and grimaced, then walked through a doorway which led into a café. Upstairs in the dayroom, a man wiggled his fingers and banged his hand repeatedly against his thigh. While this text is similar to stage directions for a performance, it is in fact a summary of the choreography of interactions, movements and gestures undertaken by residents of a Stockholm elder care residence.

## Background

From 2017-2019, an interdisciplinary team of art, design, elder care and nursing researchers from the Karolinska Institutet, University of Arts Stockholm, Konstfack, Stockholm University and RMIT University investigated how space and place was inhabited and perceived by residents, staff and family members of two elder care residences in Stockholm.<sup>1</sup> facilitated co-design workshops, interviews, observation

---

<sup>1</sup> *Co-design for Better Experiences in End-of-Life Settings: A Transdisciplinary Project* commenced in October 2017 with funding from Swedish Research Council Formas and with Stockholm Elder Care Bureau as the project partner. The title of this project is also referred to as *Space and place in end-of-life care* by the research team.) The project was led by Ida Goliath (Karolinska Institutet) and the research team, Professor Bo Westerlund, (Konstfack), Professor Rebecca Hilton,

studies and artistic residences to ascertain how the inhabitants of the Serafen and Mälärbacken elder care residences inhabited and responded to the spaces within these facilities.<sup>2</sup>

The researchers' expertise and methods spanned action research, nursing and palliative care, aged care, choreography, social practice and co-design. The project contributed to the *DöBra Transdisciplinary Research Program* (2014-2018)<sup>3</sup> which hosted projects investigated perceptions of death and dying, facilitated conversations about death, dying and bereavement, explored space and place in elder care residences and contributed to change processes and policy within and about end of life settings.<sup>4</sup>

A sub project, *Choreography of Care* engaged choreographic and ethnographic practices to observe and document the care and lived experience of elderly residents of the elder care residence and the staff and family who cared for and visited them. Elder care residences such as Serafen are extremely physical environments where residents, nursing and ancillary staff, family members, volunteers and cleaners are a community of people in constant motion, performing and receiving essential and continuous acts of care. In this choreographic ecosystem, nursing staff care for residents in the wards, respond to patients who have pressed call alarms, walk quickly through corridors, administer medication and write notes. For this article, these patterns, systems and processes will be considered as a form of choreography. As such, the focus of this article is on choreography as a tool to understand the range and role of movements and gestures of people who inhabited the elder care residence, rather than as a practice for composing, notating and organising movement for performance outcomes. In addition, the

---

(University of Arts Stockholm), Annafelicia Nillson, Anneli Stranz, (Stockholm University), Keely Macarow, (RMIT University) and Professor Carol Tishelman, (Karolinska Institutet).

<sup>2</sup> Ida Goliath, Anneli Stranz, Bo Westerlund, Rebecca Hilton, Keely Macarow, Felicia Nillson and Carol Tishelman, 'Using Participatory Co-Design to Create Supporting End-of-Life Environments in Elder Care', poster, *16<sup>th</sup> World Congress of the European Association for Palliative Care*, (15 May 2019).

<sup>3</sup> Olav Lindqvist and Carol Tishelman, 'Going Public: Reflections on Developing the DöBra Research Program for Health-Promoting Palliative Care in Sweden', *Progress in Palliative Care* 24, no. 1 (2 January 2016): 19-24.

<sup>4</sup> Lindqvist and Tishelman, 'Going Public: Reflections on Developing the DöBra Research Program for Health--Promoting Palliative Care in Sweden,' 19-24.



paper outlines how an ecosystem of care can be understood through studying the movements and gestures of the inhabitants of an eldercare residence, which illuminates social and physical encounters between those that engage in care labour and those that receive care.<sup>5</sup>

## Methods

A two-week artistic and action research residency was undertaken in October 2017 at Serafen, a residential facility in Kungsholmen, central Stockholm. Permission and ethics clearance were given for the observation and interaction with inhabitants of two sites within the elder care residence. The researchers were provided with access to a 15-bed ward and the lobby of the ground floor of the building to observe staff, residents and visitors as they engaged in the machinations of life and work in an elder care residence. The researchers used text, photography and video to record the people and environment of the designated ward, and text to capture the nuances of the exchanges which took place in the ground floor lobby. Team members also engaged in interviews with staff and residents about their experiences working and living in the elder care residence. For my contribution to the residency, I used ethnographic<sup>6</sup> and choreographic practices<sup>7</sup> to observe and document the movements, gestures and interactions between the residents, staff, and visitors in the ward and the lobby. My concern as a creative and social practice researcher was in the choreography of movements engaged in by residents, staff and visitors

---

<sup>5</sup> Hi'ilei Julia Kawehipuaakahaopulani Hobart and Tamara Kneese, 'Radical Care', *Social Text* 38, no.1 (2020): 11.

<sup>6</sup> Sarah Pink, 'Engaging the Senses in Ethnographic Practice', *The Senses and Society* 8, no. 3 (2013): 261-267; Sally Denshire, "Autoethnography", *Sociopedia.isa*, (2013); Elizabeth Cartwright, Anita Hardon and Lenore Manderson, 'Ways of Caring', in *The Routledge Handbook of Medical Anthropology*, ed. Lenore Manderson, Elizabeth Cartwright and Anita Hardon, (New York and London: Routledge, 2016), 164-182.

<sup>7</sup> Carrie Noland, 'Introduction', in *Migrations of Gesture*, ed. Carrie Noland and Sally Ann Ness, (Minneapolis: University of Minnesota Press, 2008), ix-xxviii; Andrew Hewitt, 'Social Choreography and the Aesthetic Continuum', in *Dance*, ed. André Lepecki, (London: Whitechapel Gallery and Cambridge, Massachusetts: MIT Press, 2012), 149-151; Andrew Hewitt, *Social Choreography: Ideology as Performance in Dance and Everyday Movement* (Durham and London: Duke University Press, 2005); Gabriele Brandstetter, 'Choreography As a Cenotaph: The Memory of Movement,' in *Remembering the Body*, ed. Gabriele Brandstetter and Hortensia Völkers (Hatje Cantz: Ostfildern-Ruit, 2000), 102-134.

who lived and worked in or visited the Serafen elder care residence. The decision to study the movement and gestures of the residents, staff and visitors originated from my inability to understand Swedish, which is the primary language spoken at Serafen. While research colleagues interviewed the Swedish residents and staff about their experience of spaces within Serafen, I observed and noted how residents, staff and visitors gesticulated and moved in and through the sites allocated to our study as a vehicle to ascertain what human bodies revealed about their corporeal experience of the residential setting.<sup>8</sup> My focus was on the relationships, gestures and movements and language of the bodies (instead of the spoken language) of the people who inhabited the dayroom and corridor of a ward, and the ground floor lobby.

As a result, I spent two weeks at Serafen noting the gestures and movements of the inhabitants of the study sites in a notebook, to map what the research team called the choreography of care. A choreography focuses on the organisation of movements and gestures. Therefore, a choreography of care illuminates the ways in which the inhabitants gesticulated, moved and interacted in and through spaces in Serafen, and how these movements can be understood through the care work at this elder care setting. The choreographic research undertaken at Serafen therefore differs from the work of dance practitioners and researchers who have studied or facilitated dance events, experiences and workshops for the socialisation, entertainment, health and wellbeing of older people.<sup>9</sup>

Instead the aim was to examine the language of the bodies of people that inhabit end of life care settings and understand what their movements and gestures revealed about their bodies and the spaces that they reside in. As such the micro and macro choreographies which took place in the ward designated for our study and in the lobby were key to

---

<sup>8</sup> Although I initially developed a focus on bodily movements and gestures because of my concern I would not be able to engage in conversations with the residents, the majority of the people I encountered at Serafin could and were happy to speak English with me.

<sup>9</sup> Clary Krekula, Markus Arvidson, Satu Heikkinen, Andreas Henriksson and Eva Olsson, 'On gray dancing: Constructions of age normality through choreography and temporal codes', *Journal of Aging Studies* 42, (2017), 38-45; Kai Lehtikoinen, 'Dance in Elderly Care', *Journal of Dance Education* 19, no.3, (2019), 108-116.

understanding how the inhabitants of Serafin physically inhabited and interacted in the residential setting.

### **Social choreographies**

Gabriele Brandstetter has written that:

choreography is a form of writing along the boundary between presence and no longer being there: an inscription of the memory of that moving body whose presence cannot otherwise be maintained. Choreography is an attempt to retain as a graph that which cannot be held: movement. On the one hand, ‘choreography’ means the writing of movement as notation; on the other hand, it also refers to the text of the composition of movement. Choreography, as the writing of and about movement, as preserved memory, thus always includes something of a requiem.<sup>10</sup>

Here, Brandstetter writes of choreography as notation for performance and also as a way of understanding the physicality and mapping of social relations and activities such as walking.<sup>11</sup> If we understand choreography as the organisation of movement through time and space, then we can see choreography wherever there is movement and we can discern what gestures and movements reveal and communicate a person’s inhabitation of space and place.<sup>12</sup> As such, choreography framed my thinking around the organisation of movements and gestures in the spaces allocated for our study in Serafen. While staff and residents occupy the same spaces within the residential setting, staff also pass through and have access to other spaces that residents may not have access to or may use less frequently (for instance the spiral staircase in the lobby and offices). In addition, the elder care facility is a home to the residents and workplace for the nursing and ancillary

---

<sup>10</sup> Brandstetter, ‘Choreography as a Cenotaph: The Memory of Movement’, 104.

<sup>11</sup> Brandstetter, ‘Choreography As a Cenotaph: The Memory of Movement’, 102-134.

<sup>12</sup> Gretchen Schiller, ‘The Body Library: Chor(e)ographic Approaches to Movement, Memory and Place’, in *Choreographic Dwellings*, ed. Gretchen Schiller and Sarah Rubidge, (Houndmills and New York, Palgrave Macmillan, 2014), 138-154.

staff. This is essentially social choreography, or as writer Andrew Hewitt observes:

The aesthetic will function – and here we encounter the importance of the performative within our notion of social choreography – as a space in which social possibilities are both rehearsed and performed.<sup>13</sup>

At Serafen, the social choreography is based on a production of labour with staff tending to the care and needs of the residents. Therefore, social choreography is similar to a choreography of care where people's movements and gestures communicate and illuminate social and power relationships, such as those that exist between nursing staff (carers) and residents (the cared for). Interestingly, Hewitt views social choreography as a means of production, with performance as a social and political act, with an underlying set of conditions and ideology. For Hewitt, choreography (as for elder or any social care) is an organizing framework for political and social relations and conditions.<sup>14</sup> Hewitt's notion of a social choreography is a useful framing for the occupation of spaces in elder care residences. For instance, a production of labour and care was engaged in at the elder care residences as nurses and residents conversed, ancillary staff prepared refreshments and nurses administered medication. In Hewitt's lexicon, social choreography is action borne through politics, ideology and production.

In an elder care residence, the social choreography denotes the socialised environment of the space and the place that the performance of the body is rehearsed and performed. In addition, the social ecology of nursing staff, medical practitioners, volunteers and family members contribute physical and emotional labour to an extremely intimate choreography of care. As I observed people moving through the corridors, day room, bedrooms, offices, activity room, café, lobby and spiral staircase, I witnessed and participated in a social choreography where the movements, interactions and gestures of people's bodies intersected. I engaged in the social choreography at Serafen as I observed people drag their feet, move nimbly, rush past me, or stop to

---

<sup>13</sup> Hewitt, 'Social Choreography and the Aesthetic Continuum', 149.

<sup>14</sup> Hewitt, 'Social Choreography and the Aesthetic Continuum'; Hewitt, *Social Choreography. Ideology as Performance in Dance and Everyday Movement*.

speak. My own gestures and movements through Serafen became more confident of the space as I spent more time in the facility.

For Brandstetter, choreography is the mapping and writing of and about movements across space and time. However, if we apply Brandstetter's schema to the choreography of the inhabitants of Serafen, this writing about their movements is also a form of notation as it preserves the memory of their gestures and movements as they occurred over time and through space. My written inscription of the choreography in Serafen documents the lived experience of that place and is a summation of the movements and gestures of people who lived, worked in and visited the elder care residence in October 2017.

### **The care setting**

In Serafen, the movements and gestures of a nursing staff member will be determined by the needs of a resident who may need assistance with eating and dressing. Conversely, a resident's movements will be informed by the directions and actions of a nurse. The movements and gestures of residents and staff are also determined by the built environment of the elder care residence that they inhabit. For instance, a corridor can mean a slow walk for a person who requires a walking frame, and fast strides for a busy and agile staff member who has to reach a sick resident in a hurry.

A long L shaped corridor in the ward designated for the study provides access to a day room, bedrooms, office and a toilet for staff and visitors. The corridor is furnished with paintings and noticeboards on the walls, a sofa and chairs, pot plants and sideboards. The day room is a large sunny room comprising a kitchen and dining room where staff prepare and serve food and refreshments to the residents, who dine, converse, relax and nap in the room. In contrast, the downstairs lobby is a busy meeting space which provides access to other levels of the residence, and to an activity room and café. Staff, residents and visitors access the lobby through a number of entrances including the front door of the residence, a spiral staircase in the middle of the space and an elevator. Interestingly, the staff and residents moved through the dayroom and lobby with different energy, agency and purpose. For instance, nursing, administration and ancillary staff focus on the care of the residents and care of the residential home, while the residents are in turn dependent on receiving care.

Cartwright et.al. have written of the difficulties of care giving (and receiving) within elder care contexts and especially when care is given to and received by family members.<sup>15</sup> For many people, receiving care does not come easily after a lifetime of independence and after being used to being a caregiver themselves. Feminist scholarship of care has also stressed the importance of care and labour in the “care economy” and care workers who “support the cleaning, coddling, organizing and mending of homes, children, the elderly, and the underserved”.<sup>16</sup>

Interestingly, the movements of nursing and ancillary staff who clean, coddle, organize, mend and engage in care work tend to be faster, quicker and more dexterous than the residents who are not as busy and have less energy. A resident’s physical and mental health, mobility and wellbeing determines their ability to move through the residential wards, and other spaces in the residence (day and activity rooms, the café, the lobby) and their sociability and engagement with each other and with staff and visitors.

The tension between physically slower residents and energetic staff members reveals many different experiences of the built environment that they all inhabit, and the physical dynamic of those that give and those that receive care. The slower movements of the frailer residents and the more fluid and energetic movements of the staff (who rarely seem to stop) illuminates the diverse physicality of people who access the same spaces but have different physical needs. For instance, there are handrails and chairs at intervals throughout the corridor of the ward to assist the slower gait of the elderly residents. However, corridors must also remain free of clutter to be a clear thoroughfare for the inhabitants. In addition, the residential staff require floors that will not exasperate or cause injuries to their feet as they are literally on their feet constantly during their shifts.

### **Mapping the built environment**

During the research study, I also viewed the movements and gestures of staff, residents and visitors from a sofa positioned against a wall in

---

<sup>15</sup> Elizabeth Cartwright, Anita Hardon and Lenore Manderson, ‘Ways of Caring’, *The Routledge Handbook of Medical Anthropology*, ed. Lenore Manderson, Elizabeth Cartwright and Anita Hardon, (New York and London, Routledge, 2016), 164-182.

<sup>16</sup> Kawehipuaakahaopulani Hobart and Kneese, ‘Radical Care’, 11.

the ground floor lobby and observed as a resident walked in through a door, bent over and thrust her body forward. She then walked to the centre of the lobby, placing her hand on a rail to move onward. With quite a different energy and purpose, a staff member rushed down the staircase in the middle of the lobby, coughed and then moved downstairs to a lower level. These movements demonstrate the differences in the vitality and strength of residents and staff and how they respond physically to the same space.

My notation of the movements of the Serafen inhabitants documented vast differences in the energy and vitality of people's movements as they experienced the layout and design of the residence. This reveals the design challenges of the built environment of eldercare residences, which tend to have long corridors throughout wards for easy access for staff to move from room to room, and day rooms for meals, socialisation, activities, naps and food preparation. While the long corridors allow for multiple bedrooms to act as intimate nodes on meandering thoroughfares, the length of the corridors also presents problems for staff, becoming rushed off their feet and tired from constantly moving through these spaces. Residents who require urgent help and are based in bedrooms at either end of the corridors also run the risk of not being attended to if staff are located at the opposite end of the corridor and do not hear the residents alarm bells or voices during an emergency. The L shaped corridors are highly problematic in case of emergencies and should be reconsidered when designing care settings. In contrast, the lobby is a confined space for staff, residents and visitors to traverse to other spaces within or external to the residence. However, the spiral staircase in the centre of the lobby is a curious feature to have in a care setting because of the risk of falls. This does not appear to deter the movements of the staff who are rushed, quick and sprightly in comparison to the slower and more considered residents who traverse the lobby.

### **Mapping gestures and movements**

My interest here is in the role of gestures and movements of the people who inhabit this elder care space, however repetitive, small or intimate. My extensive notes of the actions, tasks and activities undertaken in the ward made available for the residency and the downstairs lobby reads

like a score,<sup>17</sup> or stage directions for performance.<sup>18</sup> The score traced the movements, gestures and interactions of residents, staff, family and friends who inhabited Serafen during the residency and the sonic environment of public and private spaces of the residence. Here, the score is my undertaking, it is not a participatory work of the inhabitants of Serafen. Instead, I used choreography as a method to map the movements and gestures I observed and my notes transcribed the action that took place in front of me. This is not to suggest that my score could not be adapted into a performance. Dance choreographers and theatre directors could literally adapt my notation into a choreography or an improvisation for a performance by asking performers to perform the gestures and movements that I had observed and noted. This how scores operate – they are notes which are adapted into directions for performers.<sup>19</sup>

However, my score and sensory mapping of the elder care setting not only included what I saw but also what I heard.<sup>20</sup> Sensual data which collates what we see, hear, smell, taste, touch and feel provides an indication and insight into the sensory experience of research settings. Therefore, it is important for sensory data to be collected when embodiment is a focus of the study<sup>21</sup> as it illuminates the overall lived experience (of what we hear, feel, smell and see) in the research site. For instance, deep listening within the downstairs lobby of the residence and the ward made available for the research, revealed an assemblage of sounds at varying frequencies and pitches that were emitted from humans, objects and machines, which reflects the dual purpose of an elder care residence: a workplace for staff and home to residents. The agility of the bodies inhabiting Serafen was revealed as people banged and closed drawers, shuffled as they walked, jingled keys, rustled paper, washed hands with liquid soap, banged tea cups on a table and scraped cutlery in a bowl. The sounds heard in Serafen accentuated the vigorous energy of the movements that I observed, and suggested

---

<sup>17</sup> Anna Halprin, 'Scores', *Dance*, ed. André Lepecki, (London, Whitechapel Gallery and Cambridge, Massachusetts, MIT Press, 2012), 149-151.

<sup>18</sup> Brandstetter, 'Choreography As a Cenotaph: The Memory of Movement', 102-134.

<sup>19</sup> Halprin, 'Scores', 149-151.

<sup>20</sup> Pink, 'Engaging the Senses in Ethnographic Practice', 261-267.

<sup>21</sup> Pink, 'Engaging the Senses in Ethnographic Practice', 261-267.



the energy of movements that I could not observe as they took place in spaces that were adjacent to my peripheral vision. These gestures and movements signalled much about the mobility and agency of residents, staff and visitors by revealing the energy, vibrancy and purpose of a person and the frailty and limits to their physicality. Through listening to and watching people's limbs and hands navigate through the ground floor lobby, the long corridor and day room in the ward, the choreography of the residence demonstrated marked differences in the flexibility and dexterity of residents and staff alike.

### **Choreography of the hand**

In contrast to the diversity of movements seen in the public facing lobby, a female resident was observed sitting in the dayroom of the ward with her hands clasped tightly.

*Her hands moved out of the firm grasp  
and her thumb pushed over her hand.*

*Her fingers pointed  
and her hands clasped together.*

*Her hand moved to her mouth  
and then pressed into the table.*

Here, a microchoreography reveals the language of the woman's body, which resides in the intimate gestures of her hands. The resident's hands communicate language instead of words as they point, clasp, press into a table and move to her mouth. This lexicon of the body is an intricate choreography of the hand. The resident's hands engage in simple gestures in a room where residents eat meals, converse, nap and stare into space.

Hands, as Margaret Atwood has written, notate and trace the beginning and ending of life. Our hands stroke the contours of our bodies and map the world in which we live and imagine. Despite the vastness and colour of the world, it is our bodies, and for Atwood, our hands that we always return. As we pause to breathe, and as we strive to hear the breathing of the newborn or the last breath of loved ones, it is the physical body and our hands that we use to comfort, stroke a brow, check a pulse and massage limbs. It is through our hands that we

communicate thoughts, love and touch. It is through our hands that we grasp, clasp, write, caress, toil, make, communicate, and are human.

What do you do with your fingers, hands and limbs when your mobility and energy is limited? A resident of an elder care residence may move, clasp, point and bang their fingers, while they spend time in a dayroom. The US choreographer, writer and filmmaker, Yvonne Rainer, depicted the choreography of her hand in *Hand Movie*<sup>22</sup> as she recovered from surgery. Filmed by dancer William Davis as Rainer was recovering in hospital, *Hand Movie* depicts Rainer's choreography of her hand.<sup>23</sup> In *Hand Movie*, Rainer's hand engages in a playful choreography where her fingers overlap, press and push down. Her fingers bend, cross and become entangled. Fingers curve into the palm and then rise. One by one, her fingers bend and bunch together. Fingers stroke and cross other fingers. At times, Rainer's large thumb engages in a dance with her long, slender fingers. The choreography of Rainer's hand is intricate, purposeful and sensual.

Although Yvonne Rainer was a much younger woman than the Serafen residents when she made *Hand Movie*, she was nonetheless restricted with the movements of her body. The choreography of her hand was undertaken when the movement of her entire body was more limited due to her confinement within a hospital setting. As Kyle Bukhari observed,

Rainer has displaced the dancer with a hospital patient (herself), the body with the hand, and dance with a choreographic experiment. The move into the two-dimensional realm of film displaces the live performance of gesture and replaces ephemerality with persistence.<sup>24</sup>

---

<sup>22</sup> Yvonne Rainer, *Hand Movie*, 1966,

<https://www.youtube.com/watch?v=5xSKgl4Dd5o>.

<sup>23</sup> Kyle Bukhari, 'Movements of Media in Yvonne Rainer's *Hand Movie* (1966) and Richard Serra's *Hand Catching Lead* (1968)', *The International Journal of Screen Dance* 8 (7 June 2017); Colleen Kelsey, 'Screen Time with Yvonne Rainer', *Interview*, 20 July 2017, <https://www.interviewmagazine.com/film/yvonne-rainer-the-film-society-of-lincoln-center>.

<sup>24</sup> 'Movements of Media in Yvonne Rainer's *Hand Movie* (1966) and Richard Serra's *Hand Catching Lead* (1968)', 61–62.

Interestingly, the movements of the hands and limbs of the Serafen residents and staff also reveal a persistence with movement, as we have seen with the repetitive banging, pressing of fingers and hands. However, the choreographies of the bodies of the people of Serafen differ because of the extremities and limitations of their corporeality, and because of the role they perform as staff member, resident or visitor. Just as Rainer's film demonstrates the extensive movements that her hand can engage in, the choreography of the bodies of the residents and staff of Serafen also display a range of actions and meanings.

The choreography of the inhabitants that move in and through the Serafen elder care facility (including the author of this article) reveal the language and relationships of the bodies that inhabit the residence. For instance, the tasks, activities and care for residents is expressed and activated through the physical movements and gestures of the staff. Conversely, the residents receive care through the hands and bodies of the staff who attend to them. As such, the embodied lived experience of the elder care residents, staff and visitors reveals their relationships to the space they inhabit and to each other. This connects to a key aim of the research team which was to highlight the relationship between embodiment and space and how the demands on the end-of-life care setting are negotiated and experienced by the inhabitants.

Not surprisingly, the hands of staff are critical to the care of the elderly residents and the labour they perform within the elder care residence. In the day room, a staff member poured tea, moved her body in a circular fashion, pulled a chair from a table, leant down and laughed. In the adjacent corridor, a staff member clasped the hand of a man who was sitting in a wheelchair. Our hands are important to social connectivity, interaction and conversation as they denote our tension, anxiety, humour and pleasure. The repetition of the gestures of our hands indicate the language of our bodies and the limitations of our physicality. Some people are expressive with their gestures and movements while others might be restricted through arthritis in the joints of their fingers which limits movement and causes pain. The intimate gestures of our hands are particularly meaningful when we are frail and cannot move our bodies with as much flexibility or rigour as we may have in the past. We communicate through our hands and use them to wave in greeting and to demonstrate our affection through

touch. This becomes particularly important as we slow down due to the physical limitations of our bodies and impairment of our limbs.

### **Choreography of Care**

The choreography of the hands and limbs of the people who inhabit Serafen revealed great differences in interactions and movements as they walked, strode, rushed, laboured and manoeuvred wheelchairs through the public and private spaces of the elder care residence. Here mobility and ability in moving limbs and bodies varied depending on one's role, purpose and corporeality. For instance, it can take a long time to use utensils and move limbs if your body is not agile or mobile.

Observations undertaken during the residency at Serafen revealed how residents, staff and visitors engaged with furniture, utensils, crockery, hygiene, rooms, handrails, wheelchairs and other humans. For residents, the debilitating and slow movements of disabled hands and limbs can mean that much time is taken to undertake what more dexterous and flexible people would find the simplest of activities.

The choreography of care that is being enacted through the movements of people in and through elder care residences is a scenario that many of us will be familiar with at some stage of life either through our lived experience as a visitor (family member, friend, volunteer, carer) or as a resident. It is also critical that we understand how people inhabit their bodies and the spaces of elder care residences, as this knowledge assists the lived experience of those currently living and working in and visiting elder care facilities, and for those of us that may frequent and reside in these settings in the future. The ways which we interact and move through elder care residences provide us with information on how well the spaces and places in these settings are designed and operate for people at the end of their lives.<sup>25</sup>

However, while the gestures and movements of the bodies of people with limited mobility may appear repetitious and slow, these microchoreographies should also be considered within the vicinity of the time and space in which they are expressed. In other words, how much can we achieve within the limitations of our bodies and homes when we are frail? Where we may have once used our physicality to

---

<sup>25</sup> Laurene Vaughan, 'Design as a Practice of Care', in ed. Laurene Vaughan, *Designing Cultures of Care*. London: Bloomsbury, 2019).

demonstrate our strength, energy and vigour, we may now use other more intimate gestures to communicate. Hence, the meanings behind our movements and gestures will also change as our bodies slow down and become frail.

Furthermore, we cannot escape the signs and failings of our own bodies, or the illnesses of loved ones, as we engage with others to research and maintain health and wellbeing. We may use ethnographic and choreographic methods as I have done to observe, explore the physicality and wellbeing of other people, but it is equally important that we do not disavow the language and signs of our own bodies as we engage in relational practices and projects. After all, the authenticity of lived experience is critical to understanding and responding to the experiences and conditions of other people bodies; including in this case study of the inhabitants of the Serafen elder care residence.

We can see from this article how choreography can elucidate how staff, residents, visitors and this researcher interact, converse and inhabit spaces within care settings such as an elder care residence. As crucial as clinical practices and knowledge systems are, we should also be guided and informed by the haptic, sensory, emotional and physical lived experience of our bodies as we seek to understand the experience of people inhabiting care settings. It is the combination of the lived and researched experience of care settings which will enable knowledge of the ways in which such spaces are used, inhabited, responded to and designed. For instance, I have written how choreography can be used as a tool to illuminate how bodies move in and through spaces, and how spaces operate as a result of our movements. Here, choreography can assist our understanding of the physicality of care settings such as elder care residences. I suggested earlier that the choreographies observed at Serafen could be adapted into performative outcomes. However, I also recommend that architects and designers who design for health care observe the daily physicality and lived experience of inhabitants of elder care residences to understand the use and limitations of these care settings. This knowledge can then inform their adaptation of contemporary care settings for a range of mobilities, competencies and experiences and assist their development of future facilities and residences. This can only be a positive outcome as we in turn visit or inhabit elder care settings ourselves.