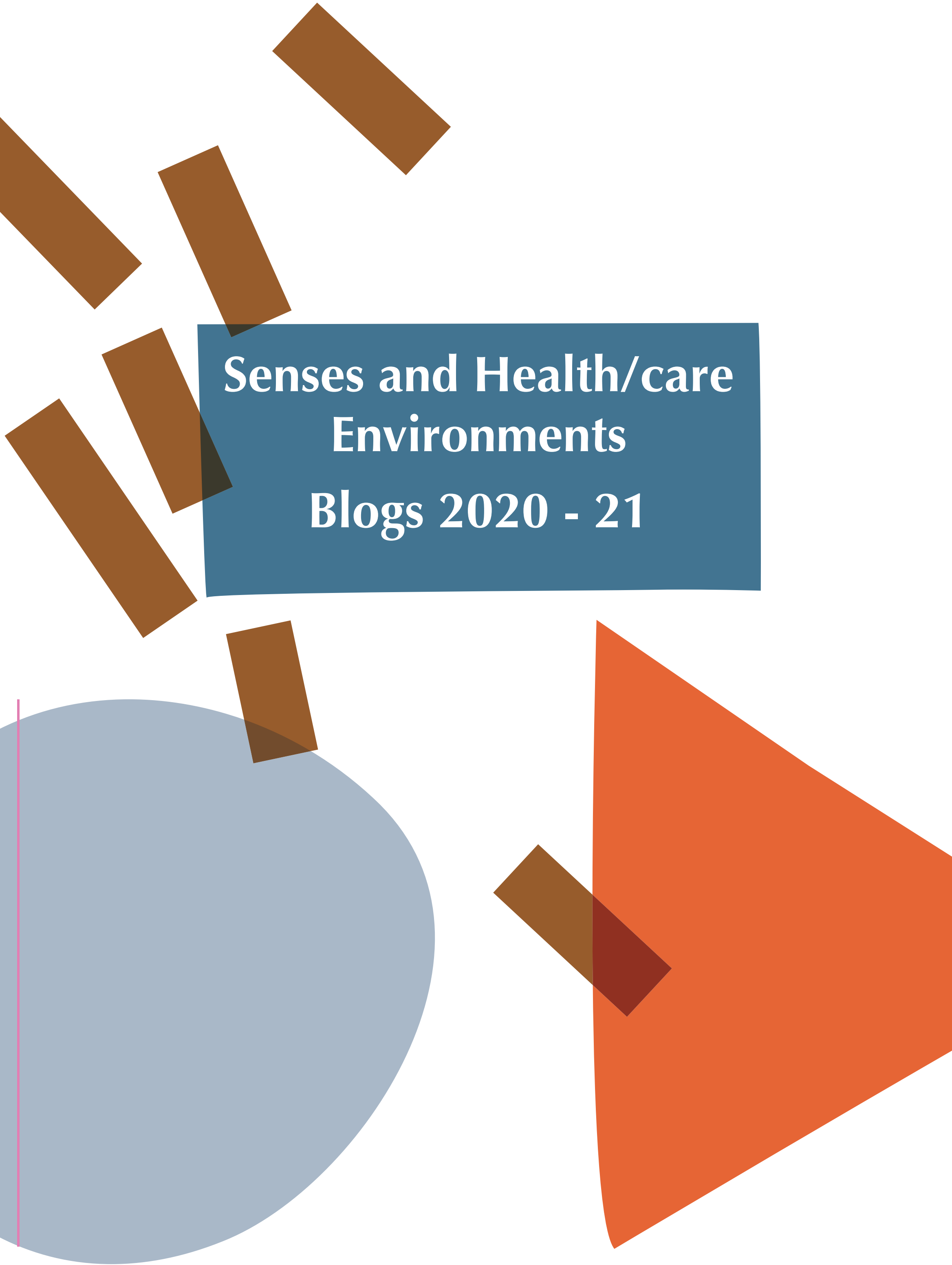

Senses and Health/care Environments

Blogs 2020 - 21

Starting in summer 2020, we invited website contributions from members of the Senses and Health/care Environments network (Wellcome Trust) and others working on subjects relevant to the Sensing Spaces of Healthcare project (UKRI). We summarise these here as ‘blogs’, but this is shorthand for a range of contributions from interviews to audio-visual and creative contributions. In 2021 we compiled the first 11 blogs as a printable booklet, so that people can enjoy reading them away from a computer screen. Thank you to Pirrip Press for the booklet design.

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June 2020

Hospital Architecture Beyond The ‘West’

by Sara Honarmand Ebrahimi.

Church Missionary Society (CMS) hospital in Kerman © the author

Since March, besides being worried and reading and writing in between, I have been thinking about the term ‘Eurocentrism’ more than ever. COVID-19 has brought a wide array of discussion and reflection on various topics, including previous epidemics, hospital visiting, care, and health/care environment. At the beginning, I read many blog posts and some articles, but, as times went by, I stopped. I did not stop because the articles I read were not important, but because they were Eurocentric.

Of course, this judgement is not all-inclusive. I came across many of those posts and articles via my Twitter page. I have also been limited by my language abilities. I am sure that many non-Eurocentric articles have been written in non-European languages, but whether or not they reach a wide audience is the question, and the problem for that matter. I can say with some degree of certainty that many of them do not. In this blog post, I wish to highlight some of my thoughts on this, which are, of course, open to criticism and correction.

I would like to take hospital architecture as an example. We know about the development of hospital architecture in Britain in detail: Florence Nightingale’s *Notes on Hospitals* is believed to had revolutionised hospital architecture in the nineteenth century; scholars have also examined archived journals such as *The Builder* and English-language publications on the history of hospital architecture such as the four-volume *Hospitals and Asylums of the World*.[1]

Let us consider similar publications on healthcare architecture in a country like Iran. The first book published in Farsi (Persian) on healthcare architecture by the German-trained Iranian architect, Nouradin Kianouri, in 1949 has completely been neglected, if not forgotten all together. Indeed, we know nothing about the history of healthcare architecture in twentieth-century Iran. In other words, we do not know 'how we got here'.[2] This is rather surprising given that around 150 hospitals were built across the country between 1925-1979.[3] A similar argument is applicable to other countries in the region, as among a handful of books that deal with hospital beyond the 'West', only a few discuss architecture.[4]

The reasons for such a neglect are, of course, varied. Perhaps this is partly due to an emphasis of the field of global architectural history on encounters, connections, and transactions rather than building types. This is being done for a good cause: to damage 'the largely Western narrative spun in standard architectural histories' by bringing to the fore the agency of unconventional (non-Eurocentric) actors.[5] However, such an emphasis on one over the other might have an opposite effect in the long run, at least when it comes to hospital architecture.

Returning to healthcare environments and recent reflections on past epidemics: hospital visiting is a topic of personal interest to me. It is a multi-sensory experience that is affected (encouraged or governed) by the built environment.

In their opinion article, *Hospital Visiting in Epidemics: An Old Debate Reopened*, [6] Graham Mooney and Jonathan Reinarz state that rules governing hospital visiting 'have differed from nation to nation and from institution to institution, depending on the prevailing cultures of care, the type of diseases or illnesses, and the attitudes of health care professionals.' I have found examples of such diversity in my work on mission hospitals in early twentieth century. As visits from family and friends were increasingly being policed in British hospitals, missionaries of the Church Missionary Society (CMS) allowed patients to have tea parties with their family members and smoke water pipe in the Kerman hospital (southern Iran) (Figure 1).[7]

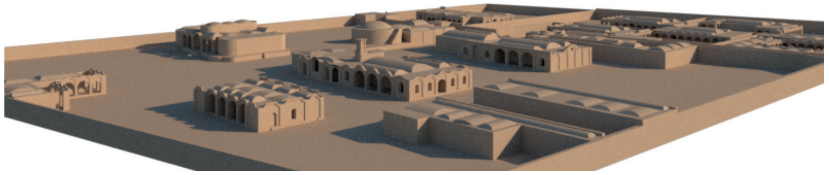

Figure 1. A 3D model of the Church Missionary Society (CMS) hospital in Kerman. Drawn by the author. © the author

If such practices were not enough, they designed a hospital building in Peshawar (North-western British India, now Pakistan), consisting of a set of 30 identical rooms around three sides of a courtyard, similar to a caravanserai – an inn for travellers built along routes in the Middle East and Central Asia. Missionaries put each room at the disposal of a 'whole family' and this system became known as the 'serai system' (Figure 2).[8]

Figure 2. The CMS missionaries used a caravanserai as the hospital in Yazd. The serai building in Peshawar had a similar room arrangement. Source: Mrs. Napier Malcolm, Children of Persia (Edinburgh and London: Oliphant, Anderson and Ferrier, 1911), 90.

Michelle Renshaw has made a similar observation concerning patient visitors to American mission hospitals in China. Renshaw further makes a comparison between 'family-centred' care in children's hospitals in today's America and those of mission hospitals in China, referring to the later as 'manifestations of the American hospital from which the family was never excluded'. [9] It is unlikely that American hospitals today drew on mission hospitals of the nineteenth century, but Renshaw's comparison is tantalising. Without it, one might pin the development of 'family-centred' care in the 'West'.

It cannot suffice to analyse developments and experiences in the 'West' when discussing 'how we got here' and, by extension, what we can learn from the past. As the current COVID-19 pandemic brings spaces of healthcare to the fore, it seems more important than ever to take the topic of healthcare architecture beyond the 'West' seriously.

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[1] Henry C. Burdett, *Hospitals and Asylums of the World: their Origin, History, Construction, Management, and Legislation,* 4 vols (London: J. A. Churchill, 1891); See for example, Jeremy Taylor, *Hospital and Asylum Architecture in England 1840-1914: Building for Health Care* (London and New York: Mansell Publishing Limited, 1991); Jeremy Taylor, *The Architect and the Pavilion Hospital: Dialogue and Design Creativity in England 1890-1914* (London and New York: Leicester University Press, 1997); Harriet Richardson, (ed), *English Hospitals, 1660-1948: A Survey of their Architecture and Design* (London: Royal Commission of the Historical Monuments of England, 1998).

[2] Annmarie Adams, "Canadian hospital architecture: how we got here," *Canadian Medical Association Journal 188,* no. 5 (March 2016): 370-1, DOI: https://doi.org/10.1503/cmaj.151233

[3] Based on materials available at the National Library and Archive of Iran (NLAI).

[4] Fabrizio Speziale, ed., *Hospitals in Iran and India, 1500-1950* (Leiden and Boston: Brill, 2012); Mark Harrison, Margaret Jones and Helen Sweet, eds., *From Western medicine to Global Medicine: The Hospital Beyond the West* (Hyderabad: Orient BlackSwan, 2009); Jiat-Hwee Chang, *A Genealogy of Tropical Architecture: Colonial networks, nature and technoscience* (London and New York: Routledge, 2016), Chang discusses the translation of pavilion plan hospitals in the tropics in chapter 3; Samuel D. Albert, "Egypt and Mandatory Palestine and Iraq," in *Architecture and Urbanism in the British Empire*, ed. G. A. Bremner (Oxford: Oxford University Press, 2016), Albert only refers to one mission hospital built in Jerusalem in this chapter; Preeti Chopra, *A Joint Enterprise: Indian Elites and the Making of the British Bombay* (Minneapolis and London: University of Minnesota Press, 2011), Chopra discusses hospitals and Lunatic Asylums in chapter 4.

[5] Sibel Zandi-Sayek, "The Unsung of the Canon: Does A Global Architectural History Need a New Landmarks?" *ABE Journal* [Online], 6 (2014), DOI: https://doi.org/10.4000/abe.1271

[6] Graham Mooney and Jonathan Reinarz, 'Hospital visiting in epidemics: an old debate reopened', *History and Policy*, 9 April 2020, https://www.historyandpolicy.org/opinion-articles/articles/hospital-visiting-in-epidemics-an-old-debate-reopened

[7] Florence M. James, "Kerman Then and Now," *The Mission Hospital* 42, no. 482 (1938): 62.

[8] "Items: Home and Foreign," *Mercy and Truth* 13, no. 146 (February 1909): 38.

[9] Michelle Renshaw, "'Family-Centred Care' in American Hospitals in Late-Qing China," in *Permeable Walls: Historical Perspectives on Hospital and Asylum Visiting*, eds., Graham Mooney and Jonathan Reinarz (Amsterdam and New York: Rodopi, 2009), 56.

July 2020

Interview: Marie Allitt

We invited Marie to tell us more about her work on the senses in First World War medical-military spaces.

What is your research about?

My research focuses on spaces and senses in healthcare and medicine, examining caregivers' life writing and illness narratives. Lately, I've made initial steps to explore the weight of the senses in remembered and imagined, literal and figurative medical spaces. My current employment in medical education has made me increasingly aware of the senses in the medical school.

The majority of my research up until now has been developing my PhD thesis, which focused specifically on First World War caregiving with the emphasis on experiences and articulations of spaces and senses. By exploring the experiences of doctors, nurses, stretcher bearers, orderlies, and ambulance drivers, and crucially the ways they represent those experiences, I examine the complexities that accompany both the experience and the attempt to articulate and communicate it. The content of such work is typified by proximities, touch, odour, cries, so it is saturated with sensory cues. This research intersects with trauma and mental health; memory and witnessing; truth and authenticity; the struggle to articulate, and the failures and possibilities of language, so these considerations are never far from my mind. This has been an interdisciplinary project: rooted in literature, it is influenced by history, human geography, and medical humanities.

Tell us about the book you are currently writing.

I'm currently developing the monograph that stems from this PhD research. The central aspect of this book, and in terms of its

Credit: World War I: stretcher bearers of the Royal Army Medical Corps (RAMC) lifting a wounded man out of a trench. Painting by Gilbert Rogers. Credit: Wellcome Collection. Attribution 4.0 International (CC BY 4.0) greater contribution, is the way in which I utilise *geographies*. Specifically, 'geographies' in the plural, encompassing spatial, sensory and sensuous, phenomenological, textual, affective, and psychological. I make the case for a specific spatial lens for critical medical humanities, as a way to understand different structures of experience that influence health and clinical experiences, for both patient and caregiver. I've found that engagement with concepts from human geography and spatial theory have been most useful in this research, allowing me to develop conceptual frameworks that I hope to expand to other contexts.

Over the course of the book I address questions concerning: the identification and characteristics of military-medical spaces; the relationship medics have with their specific environment; how medics represent their encounters with wounded bodies; how they write their roles as witnesses and articulate their complex roles as caregivers. I have sought to centralise the medical figure in the context of the First World War, applying a literary-critical approach to the role and writings of medical personnel in order to shed an important light upon their perspectives, and establish the value of their own words, as both testimonies and representations of experience.

Who should read it and why?

First and foremost, this book will be of most interest to medical humanities researchers, especially those looking for an explicit literary slant. The spatial focus will be an important contribution to the direction of medical humanities, with the field's increasing focus on objects, spaces, and emotions. This work strives to develop from the centralisation on the doctor-patient encounter, to consider the seemingly innocuous and non-human aspects that hover in the background of clinical/medical/health encounters. The book will also appeal to those interested in First World War narratives and military medicine.

What got you interested in this research area?

I arrived at the focus on senses and spaces following my interest in both First World War literature and medicine/medical humanities. My MSc by Research focused on the traumatised body in First World War literature, and by this point I knew that my research going forward would be both a focus on spaces and senses, and medicine more specifically. This was quite an obvious trajectory for me, in terms of topic.

My explicit interest in the senses in this context was influenced by Santanu Das' *Touch and Intimacy in the First World War* (Cambridge University Press, 2006), which in turn introduced me to Paul Rodaway's *Sensuous Geographies: Body, sense and place* (Routledge, 1994). I could very quickly see that the senses and spaces had been overlooked in the medical experiences, but that there was significant and vital work to be done through this lens. Since embarking on this research route, I am further convinced of the importance of a spatial and sensory lens, as well as a focus on the senses and spaces in their own right.

Where and how did you locate sensory experience in historical sources?

My background and disciplinary position in literary studies means that my engagement with the material is principally literary analysis. The specific primary sources I use for this research are rich in description and reflection on their surroundings, often mentioning what they see, smell, hear, and touch. Opening up the idea of 'senses' to complement and incorporate multiple geographies has been an effective approach, and allowed me to access the sensory experiences in greater depth.

For example, through a focus on the somatic and sensuous situation of the medic, I have been able to explore how bodies in war necessarily adapt to ongoing changing landscapes, a need which is especially heightened at the intersection of military and medical spatial geographies. The medics' bodies are mutually implicated in the landscape and with the bodies of the patients. The experience demands an intensely multisensory attention and hypersensitivity: haptic, auditory, and olfactory geographies become integral to the negotiation of space.

Why do you think the 'sensory' is a useful way of examining or understanding your topic?

When it comes to the body, there is no denying the centrality and importance of the senses. It is precisely what connects the body, the selfhood, and the surrounding world. I approach the senses in a similar vein to Rodaway: 'the senses both as a relationship to a world and the senses as in themselves a kind of structuring of space and defining of place.'[1] The senses structure and help mediate our world, and are heightened when medicine and health are involved. The caregiving experience (perhaps all caregiving contexts to varying degrees) is crowded with senses: proximities of bodies, the touch that is necessary and challenging; the pervasion of odours; the sounds of the body, that transmit signs and signals.

For me, the sensory cannot be extracted from the spatial, so I very much hold the two together. I maintain that we cannot understand (individually, intellectually, conceptually) the spaces without paying attention to the senses. The senses are vital sources of knowledge, providing networks of stimuli and information, deriving from multiple directions. Spaces make us just as much as we make spaces.

From this research, what have you learned about the role of the senses in the making of healthcare environments?

This research has confirmed that medical spaces are shaped by the experiences that take place in them, and in turn those spaces shape experiences. The sensory involvement of the caregiver tends to be overlooked, perhaps because it is assumed that the medic is only doing their job, so their experience of the space is not all that interesting. This research has reinforced that this is not the case, as even the seemingly most mundane aspect of the work is infused with complex sensory and spatial engagement, to which we need to pay more attention, in order to better understand past, current, and future healthcare environments. The stretcher bearer who clears blood from the patient's eyes; the nurse who adds more gauze and pressure to a sudden haemorrhage; the surgeon who wipes his saw ready for another amputation, are deeply embedded in the sensory and spatial landscape of medicine.

It has also revealed how close the embodied senses are to other modes of engagement: it is difficult to separate the affective from the sensory. For example, in focusing on wound care, touch, smell, sound, and sight are directly entwined with disgust, fear, and sometimes anger.

What key text would you recommend to somebody interested in your research area?

In terms of primary sources, I recommend Mary Borden's *The Forbidden Zone*, which was first published in 1929 and republished in 2008. It has become a popular text to look at in terms of nursing experiences, and women's war writing. A quick look at this text demonstrates some of the richness of such sources; it, and many others, are shocking, graphic, gruesome to some, demonstrating the depth of insight into caregiving experiences. For secondary works, the aforementioned *Touch and Intimacy in the First World War* (2006) by Santanu Das, as the title indicates, provides detailed focus on touch in relation to First World War combatant experiences, and offers some initial discussion on nurses' experiences. Both of these sources can provide a sense of the textual landscape in this area, and demonstrate the value and richness of the sensory approach.

What can your research tell us about current-day challenges or concerns in healthcare design?

This explicit research into First World War medicine, and the specificity of my sensory and spatial approach, demonstrates the perpetual role of the surroundings and environments in which treatment, care, and medicine is enacted. Simultaneously, it illustrates the importance of the caregivers' own experiences, articulated through their own words.

One of the strands of this research has focused on temporary and improvised hospitals and medical spaces. Perhaps we've been complacent that such a concept is so heavily a thing of the past, and yet recent events have demonstrated that there will always be a need to erect emergency medical provision; whether in the form of fully formed temporary hospitals, re-appropriated field hospitals; bases for first aid, or contingent sites for first responders.

In the current context of COVID-19, medical spaces have become a major concern, arguably more than ever before. Not only are we all having to negotiate spaces in different ways, the acts of caregiving have had to adapt to new ways of giving care. For example, the improvisation of isolation rooms, or the careful negotiation between infected and non-infected persons, demonstrates the delicacy of bodily movement, and how much of our experience is fundamentally shaped by the senses.

When it comes to reading the future stories and accounts of caregiving in the time of coronavirus, we will not be able to miss the emphasis on spaces – and more importantly, the manifold geographies of such experiences (whether caregiver, patient, or family).

Looking closely at historical medical experiences and histories of medicine actively contributes to our understanding of what makes a medical space: what makes it workable, bearable or unbearable; how does it feel to work in a crowded environment; how does the proximity of other patients impact the act and quality of caregiving. Such research contributes not only to healthcare design, but also clinical cultures and medical practice.

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[1] Paul Rodaway, *Sensuous Geographies: Body, sense and place* (New York and London: Routledge, 1994), p. 4.

July 2020

A patient's experience of surgery and hospitals during a pandemic

In this blog post, I'll be talking about three inherently sensory and emotional transformations that I noticed between April and July 2020. In this time period, I was diagnosed with recurrent tumours; as a result, I had several appointments, major surgery, and seven day stay in hospital.

It's worth noting that I had major surgery under normal conditions several years ago. As such, I'm able to compare what it was like then to what it was like this year.

Telephone appointments

When you're in the run-up to major surgery, you typically have several face-to-face appointments with your consultant before your operation date. You normally have an initial diagnosis appointment at which you are told the details about what's wrong, and then a follow-up appointment to give you further details and context about your surgery.

As a result of the pandemic, I had the majority of my appointments over the phone. For example, in April 2020, at the height of the pandemic, my consultant told me over the phone that my tumour had come back and that I was going to need treatment. While it was safer for my consultant to tell me over the phone instead of bringing me into hospital, it was much harder to process mentally.

The appointment did not require physical attendance at the hospital – which I usually find very stressful – so I had not psychologically prepared in the same way that I normally would. Typically, the thought of going into the hospital for my check-ups is usually enough to convince me that there is something wrong. Receiving the news outside of the hospital was far more shocking. It was also harder to ask questions because I was not physically with my consultant.

Telephone appointments also have an effect on your ability to translate medical jargon into non-specialist language. When you can't see your consultant's body language and other non-verbal cues, you lose vital pieces of information that tell you important things, like the severity of the condition that your consultant is explaining. This challenges your ability to predict and interpret what they are about to tell you, which can dramatically increase your anxiety.

Masks

Masks have the ability to dramatically reduce the spread of COVID-19 and they are vital within hospital settings. I also found that they had some interesting effects on communication

When you are experiencing face-to-face care, it is of paramount importance that you can communicate your pain levels to the professional who is looking after you. In my experience, pain is one of the hardest things to communicate, regardless of whether you're in hospital or not. It's so subjective in nature, and the words you use to describe it are so personal and unique to you. If you do end up feeling like your pain has been misunderstood, it can be a distressing and isolating experience.

On one occasion, I found myself feeling frustrated and misunderstood when I was trying to communicate my pain to a professional within the hospital. I was not wearing a mask (due to the tubes in and around my nose), but the professional I was talking to was wearing a mask. I felt that she didn't understand the nature of my pain or how much pain I was in. This was made even worse by the fact that I couldn't see her face or her facial non-verbal cues; as such, what she was saying lacked emotional context which added to my frustration.

Because of the potential for the above to occur, I found that some medical professionals tended to over-communicate. They were incredibly animated, especially with their voices and hands. A physiotherapist actually went out of her way to tell me that she had a very expressive face, that wasn't entirely visible with her mask on. Even though I couldn't see her face, this made me feel much brighter and like I had a real connection with her.

Visiting

During the pandemic, visiting in hospital has turned virtual. Keeping in touch with loved ones is reliant on visuals and sound – an experience that is devoid of touch and smell.
Touch and smell are the two senses that connect me to my family and loved ones the most - whether that be through hugs or through the scent of home, familiar laundry detergent, or perfume. Not being able to see them or my partner was probably the most challenging thing of all.

Professionals within the hospital, particularly nurses, can be affected by this. I felt that I needed and wanted far more attention from the nurses who were looking after me. This is not something that has happened when I've stayed in hospital before, as my family were typically the ones catering to my emotional needs.

Receiving treatment during this time was even stranger than I had imagined. I can't even begin to imagine how stressful it is being the ones to actually carry out the treatment, and for that, I have endless gratitude and respect for those who work in the NHS.

September 2020

Ambiences for Complementary and Integrative Practices: The therapeutic potential of architecture and interior design in Brazil

by Mariana Silva Villela.

In this blog I explore ambiences for Complementary and Integrative Practices (CIPs) in Brazil. I ask how staff and users' 'well-being' can be benefitted by architectural and interior design, from the reception and waiting room environments to the treatment room, especially for people who are more sensitive to environmental stimuli or find it more difficult to relax.

The term CIP is used ostensibly in Brazil (and officially in the public health system) as equivalent to the medical systems and therapeutic techniques popularly known as Alternative Medicine and defined by the WHO as Traditional and Complementary Medicine.[1] Users in CIP treatments do not always call themselves patients. In therapies performed in individual sessions (such as craniosacral therapy, shiatsu, etc) the therapist's aim is usually to lead the person being treated into a state of concentration, relaxation and receptivity to therapeutic techniques. CIP needs to be done in one session, on average lasting 30 to 60 minutes. In Brazil, these practices have been present in the public health system since 2006.

My research, carried out in three case studies, explored users' 'well-being' in this type of environment and the environmental stimuli that influence it. I looked at *The Centro de Práticas Naturais* (Center for Natural Practices), clinic-school of the Naturology course at the *Universidade do Sul de Santa Catarina* (UNISUL) in Palhoça, Brazil; the *Projeto Amanhecer/NUAM*, at the *Hospital Universitário Professor Polydoro Ernani de São Thiago* at the *Universidade Federal de Santa Catarina* (UFSC) in Florianópolis, Brazil; and the Spa & Wellness Center, the spa-school at the *Universidade Anhembi-Morumbi* in São Paulo, Brazil. I identified the following as important for feelings of 'well-being': Welcomeness (feeling at ease in the environment), Motivation (willingness and motivation for therapy), Beauty (perception of environmental aesthetics), Concentration (degree of attention to the therapy), Trust (feeling safe and free of phobias for therapy), Relaxation (prior tranquility and rest during therapy) and Simplicity (perception of environmental aesthetics free from excesses).

Taking the waiting room of the spa-school at the *Universidade Anhembi-Morumbi*, in São Paulo, Brazil as an example, I identified several sensory stimuli that benefit users' sense of 'well-being' in therapeutic CIP environments.[2] The 1,162 m^2 spa has individual rooms, a swimming pool, hot tubs and other resources. The waiting room, however, is one of the places that attracts the attention of not only its users, but also some of the employees of the university where it is located (Fig. 1 and Fig. 2). One of the research interviewees, a university administrative employee, reported that she usually goes to the waiting room during her lunch break, lies down on a chaise longue and relaxes for a few moments. She said that her work is stressful and that just staying there for five minutes brings her to a state of tranquility. In the waiting rooms, in all the case studies, it was common to observe the behavior of people waiting for care in an introspective state, contemplating the environment, reading, as well as little interaction between them. Visually perceptible stimuli can be designed with the aim of helping people access states of tranquility, contemplation and relaxation in moments prior to treatment.

The spa waiting room includes 7 out of the 10 stimuli identified as positive in the therapeutic environments of CIPs: Artistic (presence of decorative and/or various artistic elements), Auditory (presence of silence or soft music), Biological (absence of toxic and /or contaminating agents), Luminous and Hygrothermal Comfort (presence of natural and/or artificial resources to control lighting, ventilation, temperature and humidity), Spatial (presence of elements and attributes configured from the building and its interior environment, such as shape, fenestration, colors, coverings, layout etc. that favor the performance of activities and promote positive feelings), Natural (presence of natural elements such as vegetation, water, natural sounds or views of nature) and Social (possibility of social relationships and social support). The other stimuli identified in the research — but not in this waiting room — are Energetics (anchoring vital and spiritual energy for treatments), Olfactory (presence of pleasant aromas) and Socio-Spatial (presence of spatial configurations that favor privacy, control of the environment and territoriality).[3]

Figure 1 and Figure 2 – Waiting room called Mandala, at the Spa & Wellness Center, São Paulo, Brazil. Source: personal archive. © Mariana Villela

When people move from waiting rooms to their individual therapies, the prevalent stimuli shift to the non-visual, such as Auditory, Olfactory and Luminous and Hygrothermal Comfort. Silence (or the presence of soft music) is highly valued in these cases, as it favors relaxation, especially from the moment the person lies on the therapy bed (Fig. 3). As it is common for people undergoing treatment to keep their eyes half closed or closed during individual therapies, treatments can be carried out using a low light or dimmed light, with or without Chromotherapy resources (Fig. 4 and Fig. 5). Furthermore, when visual privacy is not possible, as in the case of an individual service performed collectively (one therapist per person served, but in a space with several beds), auditory privacy is even more important (Fig. 5).

Figure 3 – Reflexology session at the school-clinic Centro de Práticas Naturais, in Palhoça, Brazil. Source: personal archive. © Mariana Villela

Figure 4 – Individual therapy room with resources for Chromotherapy at the Spa & Wellness Center, in São Paulo, Brazil. Source: personal archive. © Mariana Villela
Figure 5 – Therapy room for Reiki at the Projeto Amanhecer/NUAM in Florianópolis, Brazil. Source: personal archive. © Mariana Villela

Concerning the individual therapy rooms, even though the person undergoing treatment (and sometimes even the therapist) often has their eyes closed during the session, the presence of a window for natural ventilation and lighting is highly valued. The positive perception of the presence of windows can be related to 'well-being' concerning temperature, safety against accidents (due to the light), absence of phobias (such as claustrophobia), among other factors that can influence relaxation.
This finding relates to Ulrich's well-known research from 1984, on how a window overlooking a garden in hospital rooms positively influenced the health of inpatients undergoing post-surgical recovery.[4] Since then, a wide range of other studies have also shown that environmental factors favorable to health, in indoor spaces, may include: the presence of windows for natural lighting and ventilation, which contribute to healthiness; noise reduction to reduce stress; the presence of restorative elements of attention, such as artistic elements or vegetation, which favor cognitive escape; and universal design, which can prevent accidents, among others.[5]

The most researched environments in the therapeutic context, however, have been those of 'Western' medicine. My work adds to this literature by considering CIPs, many of which come from specific local cultures beyond the 'West' or from so-called 'alternative' or 'traditional' health systems, and their environmental characteristics. For good architecture and design, the more we know the activities, behaviors and expectations of the users of the environments, as well as the sensitive qualities involved, the better they will be. This is important even if – or perhaps especially if – the objective is precisely to influence a person to disconnect from the environment around them, as is often the case in CIPs.

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[1] Examples of CIPs are: Anthroposophical Medicine, Aromatherapy, Ayurveda, Chiropractic, Floral Therapy, Geotherapy, Herbal Medicine, Homeopathy, Hydrotherapy, Hypnotherapy, Massage Therapy, Meditation, Osteopathy, Spiritual Healing, Traditional Chinese Medicine, among others.

[2] VILLELA, M. S. *A ambiência nas Práticas Integrativas e Complementares:* estímulos ao bem-estar do usuário. Florianópolis: Universidade Federal de Santa Catarina (UFSC), 2017. Available at: <https://repositorio.ufsc.br/handle/123456789/188694>

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September 2020

Glasgow’s Sick Kids: Time, Texture, Decay

A creative photographic essay by Alice Hill-Woods.
All images (c) Alice Hill-Woods

texture, decay, empty space, abandoned space, nostalgia, proximity, temporality

An old hospital stands atop a hill. At dusk, it overlooks the writhing light-beams of cars merging towards familiar routes, the fish-tank architecture of private student halls and a favoured Spanish restaurant. The looming building that used to be the Queen Mother’s Maternity Hospital was opened in 1964, with Yorkhill’s Royal Hospital for Sick Children opened in 1972. Today, its exterior is looped with warnings and devices used to instil a sense that this building is untouchably deceased. I am interested in the way that it performs, its affective power somehow increasing through its losses. This is not to say that the hospital is completely unused – since 2015, when the children’s facilities were moved south, a section of the building became West Glasgow Ambulatory Care Hospital for outpatients and minor injuries, but its vitality somehow lessened alongside its role. Could anyone be nostalgic for a hospital?

If a body is a shape of varying inferences – and a community is a network of these shapes – then a hospital is a repository of exponential meaning. This doesn’t change when those buildings that make up a hospital are vacated. Medical histories resound in subtle aftermath, textures of rubble and fox geranium. I glimpse my reflection and my body dissects: there is a spectral skin behind a door – a thousand spectral skins, stuck somewhere in time. I consider the skin of the hospital itself: window sashes peeling, ecchymosis-blue, snapped wires as broken capillaries, rough walls that come alive under temporary light. Even though access is limited, the doors remain like obituaries, bidding perpetual farewell to ghostly moving channels of love and health and illness and duty.


Clinical Mycology
VISUAL INFORMATION SYSTEMS AND SERVICE
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No smoking

October 2020

Quarantine in Siberia: An interview with Corinne Doria

Professor Corinne Doria is a historian specialising in the history of medicine, science and technology, and in histories of political ideas. She answered interview questions for our blog on the sensory experience of quarantine during COVID-19, which took the form of 2 weeks in quarantine at a sanatorium and 6 weeks in a flat in semi-quarantine (with permission to leave only for groceries).

Hello Corinne, thank you so much for this interview. Can you please start by telling us where you experienced your quarantine(s)?

I live in Tyumen, a city in South-West Siberia. Here, the lockdown begun in early April and lasted till the beginning of June. I experienced the quarantine in two different spaces: my apartment and a sanatorium where me and my colleagues were brought after two cases of COVID-19 were discovered in March at the university where I work.

What is your overriding sensory memory of the quarantine?

I can mention one preponderant sensory memory for each place. In my apartment, the image of the empty streets I could see from my windows. Even in the peak of the winter there are people moving around the city, and in springtime usually the street are animated till late in the evening. I had the feeling of staring at a De Chirico’s painting depicting unnaturally void urban landscapes. It was an ambivalent spectacle, peaceful and troubling at the same time. In the sanatorium, my prevalent sensory memory is probably the “smellscape” of my room and how it changed throughout the day. Early in the morning, when the nurse brought in breakfast, the air was filled with the smell of coffee; then, when I took the shower, it was perfume of the shower gel and shampoo permeating the air; around 11am., came the cleaning ladies, spreading in the room the smell sanitiser; the smell of food infused the air at 1 pm. and at 6 pm.; and the perfume of a different kind of shower gel and shampoo was the prevalent smell when my roommate used the bathroom before bed. Our room was pretty small (twenty square meters) and we couldn’t keep the window open for a long time (March in Siberia is still quite cold). So, even if we had an air purifier, the odours stagnated. In a way, it was reassuring because we could have the certainty not having Corona!

How did your sensory / spatial experience of quarantine interact with your emotions?

I experienced a precise range of strong emotions during the quarantine. After I was brought to the sanatorium, rage and impotent fury were the predominant feelings for the first couple of days. I felt like I was the victim of an illicit restriction of my freedom and considered the regional government's decision to keep us in isolation just because of two cases of Corona amongst my colleagues disproportionate. I didn't want to fight these feelings – in spite of people telling me to "think positive", be reasonable and consider the viewpoint of the medical authorities. I thought I was perfectly in the right to feel angry and I didn't want to inhibit these emotions. After a few days, these emotions started fading away, replaced by a sort of calm resignation. When it became clear that there was nothing I could do to change the situation, I started to adapt to the new environment. I was surprised how quickly I got used to that confined space. Calm and relaxation remained the predominant feelings of the rest of my stay in the sanatorium. I put my energy on what I had the possibility to act upon and began making that space mine.

Did the passing of time shape your sensory / spatial experience of quarantine (or vice versa)?

I would say that I developed a more acute perception of the space because of the quarantine. As I said, after the initial anger, I became accustomed to living in a limited space. I recall that when I left the sanatorium and took a cab to the city, I felt almost overwhelmed by the perception of the extent of the birch forest that I was traversing. When finally I arrived at my apartment, I found myself stepping in every room and staying for a few minutes in each of them, just appreciating that familiar and comfortable environment. I guess that this experience has made me aware of the impact that the environment we live in has on our emotions and behaviour, whether we want it or not.

How did the spatial/sensory experience of quarantine affect your human relationships (within and beyond its walls)?

During those two weeks I realized the importance of human proximity. I found having someone with whom to share the quarantine was very beneficial for the mood and helped me a lot during the two weeks I spent there. I lived for a long time in shared flats and so did the colleague I shared the sanatorium room with. We both knew that the key to get along with people you live with is to define a set of rules everybody agrees on. We almost spontaneously established a daily routine: in the morning, yoga, breakfast, work (we took advantage of not having classes to get some writing done); then lunch followed by a nap (yes!), and another work session; around 5 pm, workout with YouTube fitness videos, dinner, reading a book or watching a movie before bed. I think that my roommate and I made an unconscious effort to avoid every potential source of tension because we knew that it would have added a great load of stress to an already hectic situation. In that sense, I feel like the quarantine paradoxically helped me to develop social skills! The lockdown also really made me aware of the “social nature” of human beings. I’d say that in particular I have become aware of how social interaction is a multi-sensory activity. When I called my friends and family over WhatsApp or Zoom it was like I was having 50% of a proper social experience. Physical proximity engages the human senses in a very different way, even with no physical contact. You “feel” the person you are talking to, you share the same environment with her, hear the same sounds and noises, breath the same air. All this sensorial part was missing during the lockdown. When restrictions started to be lifted and it was again possible to meet in small gathering, I recall I felt a rush of endorphins just walking around a park with a couple of friends. This was my biology talking, and telling me that we are social animals!

What did you miss most from the ‘outside world’ during quarantine?

Besides human contact and ‘in-person’ sociability, something I missed very much was the ability to separate working and living space. Even if I live in a big apartment, the fact of my flat being at the same time and place where I delivered my (Zoom) classes and the place where I ate and slept was stressful. I started feeling more tired than how – to me – I was supposed to feel (I wasn’t going outside except to do my groceries once a week!), and less productive than what I thought I would be. It was psychological fatigue. When the lockdown began, a quite widespread reflex amongst people in academia has been “I will be able to get a lot of stuff done during the lockdown” but quickly people have become aware that it was just not the case. Isolation does not provide the optimal conditions for working, at least not in the long term.

How did you try to (re)connect with the outside world? For example, the internet, imagination, memory, visualisation?

Internet has been a precious help to get through the quarantine. I would say that during the lockdown it has been my primary connection to the outside world. I started using more than the usual platforms, like WhatsApp and Skype, and using some new ones, like Zoom or Telegram. Virtual contact was my only way I could continue engaging with the outside world, and I had to multiply the possibility of continuing reaching my friends, family and colleagues. But to be fair I haven’t noticed a dramatic shift in my use of the internet. I left my home country (Italy) ten years ago and since then I have been working in five different countries, and visited way more for conferences and research related activities. I have friends and colleagues from around the world and to stay in contact with them internet is the only way. My use of the internet to get access to news or movies also remained pretty consistent during the quarantine. When I moved to Siberia I couldn’t speak Russian and I had to rely almost exclusively to the web as a source of information and leisure. The lockdown exacerbated this situation but was not a radical shift. In a way, I was already trained! While I was having phone calls with my friends or relatives. I noticed that I used to picture, in my ‘mind’s eye’, their faces and the places they were calling me from. We obviously talked a lot about the impact of COVID-19 in everyday life. I recall picturing detailed images of their description of people queuing at the supermarket next to my parents’ house, or my cousin’s kids attending Zoom classes in their living room, or my best friend cooking dinner for her partner. I’ve always being a visual person and I was not surprised to notice my visual imagination activated in that way. Thinking about that now, I think that such pictures would have been even more vivid if I could add sounds, smell, or touching elements!

How did you try to stay 'healthy' in that kind of environment?

How to stay healthy in a hospital is indeed a fair question and I am not being ironic about that! Being forced to remain for weeks in a confined space can represent a threat for your physical and mental health. And living in an aseptic space and having your temperature checked twice a day is not of great help. As I said, my roommate and I organized our daily activities according to a precise schedule that included physical exercises, rest, work, and leisure. I think that this has been the reason why at the end of the quarantine both of us were feeling in a really good shape and in a good mood. It felt like we had had the opportunity to take time for ourselves. I asked my fellow colleagues about how they felt when they were released from the sanatorium and the majority of them gave me a very similar response. The most surprising part to me was to discover that all of us basically adopted the same "strategy" to cope with the isolation and we did it spontaneously. Survival instinct?

What was the first thing you did / where was the first place you went upon leaving quarantine?

The lockdown measures have been lifted very carefully and gradually in the region where I live. Walks around the city were authorized late in May, stores opened in late June, restaurants in July, gyms and movie theatres only in August. The first thing I did was meeting two friends of mine for a cup of coffee and drinking it while walking around the city centre. It was late Spring and it is a beautiful season in Siberia. You really can see the nature coming back to life, almost 'celebrating' the end of the winter with an explosion of green leaves and full-coloured flowers. I recall that afternoon as a moment of particular sensorial awareness. I discovered myself paying attention not just to what I was seeing but also hearing, smelling, tasting, and touching. It was probably a consequence of the partial sensory deprivation due to isolation and the overuse of vision we have been forced in to during the lockdown.

As a historian of medicine, did spending two weeks in a sanatorium make you rethink any of your own research?

I work on the social history of ophthalmology and visual impairment and I couldn't help noticing how my vision was reacting to this new environment. I noted how living in a small space makes the human eye loose its plasticity and adapt, focusing only on a small distance. This situation made me recall my work on school myopia, and in particular the first studies physicians made on eye disorders amongst students in the 1860s-1870s. Enquiring about the reasons for the high number of cases of myopia amongst the school population, they discovered that one of the most prominent causes was spending a great part of the day in a confined space. As the human eye is physiologically made for distant vision, when the visual horizon is restricted the eye loses plasticity and became acquainted to see clearly only objects that are at a short distance. It is basically the equivalent of scoliosis of the eye. I shared these thoughts with some my colleagues later and more than one told me that they had the same impression about how quarantine was affecting their own vision.

What do you think that future historians should know about your experience?

I think that the useful takeaway for a historian from what I experienced is that your professional competences as a scholar could really come in handy in the real life. And – conversely – your life's experience can be useful to your work. In our job we tend to believe that to write good history you need to develop a sort of detachment from your subject and that this is paramount to be objective about the topic you are working on.

That excludes almost a priori to make yourself the object of your own historical enquiry. But it can actually be very productive to engage in such an exercise. By analysing your experience you become aware of its composite and multifaced nature and its different aspects. By telling it and writing it down you add value to it. By sharing it you achieve connection with other people who have lived the same experience, whether scholars like you or not. It is not a mere self-centred exercise (for example what in France is called ego-histoire, which is a sort of academic exercise in which a scholar is asked to write a critical analysis of his/her own career). It is a way to recall that making history matters, and being a historian in our times is useful.

November 2020

Sanatoria, Spaces & Senses

by Isabel Raynaud.

The corridor stretched ahead of me – long, airless, devoid of natural light. The décor, reminiscent of a more hopeful time, now seemed eerie. The brightly coloured footprints on the floor and cartoon characters capering across the walls, intended to be jolly, struck an uncanny and sinister chord. Initially, it was unclear why, but looking closer, details came into view, justifying my unease. The tarpaulin membranes sealing once open doorways, the abundance of increasingly urgent warning signs and the layered mustiness of stale air and disinfectant collided jarringly with the garish decal-littered walls. This ward, once so bright, was now a much darker, more ominous space...

This is my recollection of a fleeting moment, earlier this year, when I was taken up to a COVID-19 ward in a central London hospital. This ward, designed for paediatric patients, had recently undergone an urgent transformation to accommodate a different clientele – adult COVID-19 patients. I found my experience of the ward alarming, even as a medical student who has spent plenty of time in similar environments. I could only imagine how patients, vulnerable in their sickness and distance from the familiarities of home, might be made to feel by these surroundings.

This brief and surreal glimpse into an environment of such stark contrasts brought home the core principle of my BSc dissertation, a medical history study that I wrote last year as part of an intercalated degree for medical students. My dissertation found that spaces, consciously and unconsciously, convey meanings, sometimes with deep visceral effects on their inhabitants. I explored the design of two twentieth-century British sanatoria – the Brompton Sanatorium, Frimley and the Papworth Village Settlement, Cambridge – investigating how they reflected the social views and intentions of their designers and considering the impacts this may have had on their patients. By reviewing archive material, architectural plans and the publications of their medical directors, I was able to address broader contemporary medical issues: segregation, institutionalisation and authority.

Papworth Village Settlement, Cambridgeshire (c. 1930) – Papworth presented itself as a community, with social and financial opportunities and security for its patients. (c) Image reproduced courtesy of Cambridgeshire Archives, Ely.

The sanatoria I studied each had a design ethos aimed to address the societal complications posed by tuberculosis in the poor.

They both took influence from the open-air movement, aiming to remove patients from the bustle and squalor of industrial cities to bucolic, green and – critically – remote environments. Both of them utilised work as the basis of their therapy, with Frimley using its medical authority to oblige its patients to dig gravel and Papworth initiating a scheme where recovered tuberculosis patients lived and worked in a modern industrialised village. The differences in design are critical. Frimley's design was an anachronism, taking influence from asylum architecture. It had an imposing edifice, full of meaning to incoming patients, putting them in their place by taking them out of place. Papworth, conversely, emphasised its egalitarian values through its design as a fully independent working village. It still removed patients from healthy society, but it also allowed them to escape the prejudice of the outside world and flourish, despite their diagnosis. In their designs, the medical directors positioned themselves at opposing ends of a spectrum in terms of their response to the danger posed by their patients. Frimley prioritised aspects of protection of the public and Papworth protecting the patients themselves.

Through my spatial analysis, I disentangled how these principles influenced design, considering the impacts on the patients within. Just as my visit to the COVID-19 ward left a deep impression, patients at Frimley and Papworth would have experienced conscious and unconscious responses to their surroundings. The lack of patient voice represented in primary sources makes it hard to know the full extent of these effects, but with the evidence growing surrounding the psychological and wellbeing consequences of spaces, it isn't challenging to empathise and imagine, either the impacts of authoritarian Frimley or community-based Papworth. These spaces are now crumbling relics, consigned to history – their texture, sounds and smells lost forever. But using the evidence that remains, we can start to piece together a sense of these spaces.

Research is increasingly trying to develop an evidence base for modern healthcare facilities. Reflecting on past design can inform new design – we should be thinking about the meanings represented in the architecture and layout of modern healthcare spaces. Do patients feel supported and equal to their doctors? Or have modern hospitals inherited problems of the past, making patients feel displaced, distressed and dissatisfied? Empowering patients is a key priority in modern healthcare and, as a medical student, I'd like to think we've got our own priorities straight today.

December 2020

First and Last Breath – notes on a soundscape

by Kate Binnie.

Breathing is the bookend of our lived experience; the first thing we do at the moment of birth is inhale, and the last thing we will ever do at the point of death is exhale/expire. During our lifespan, we develop our own unique breathing pattern and identity, our particular breath-signature that is exquisitely attuned to the fluctuations of our nervous system, which itself has been sculpted by myriad factors from the quality of our earliest relationships to environmental and cultural influences. Breathing is so much more than an autonomic function of the body that starts at birth and stops at death like a mechanical bellows being switched on, then off. It is an exquisitely attuned barometer of our internal landscape that – as meditators and body-mind practitioners know and have understood for millennia – can be utilised as a powerful tool for supporting psychological and physical wellbeing.

Generally in modern society however, the norm is restricted, shallow, over-fast and inefficient breathing. Many of us – almost without knowing it – are chronically anxious. We've been snatching our breath whilst busy doing other things; we're out of time and out of breath. Add-in asthma, chronic lung disease, advanced cancers and heart failure and you have a large number of people living with breathing difficulties relying on medical management, with little support for or understanding of how to improve their breath-related wellbeing. This is costly on many levels. Now add-in a global pandemic where people with breathing problems to start with are the most vulnerable to serious complications from COVID-19 infection, and who continue to be isolated, anxious and at high risk of hospitalisation, long-term problems and mortality. The pandemic has brought breathing and breathlessness into sharp focus; we dread the arrival of the COVID-19 cough and post-COVID-19 shortness of breath, we fear others' exhaled breath and airborne infection, we see the ventilators and oxygen masks on TV in intensive care units with a sense of doom.

In a less obvious way, perhaps, the experience of living through a respiratory pandemic has also brought home to us the preciousness of the free and unconscious breath; something we may have spent so carelessly up to now. Those of us lucky enough to be able to breathe freely may now be aware that this is an invisible gift, something to treasure and enjoy while we can. We breathe, we are alive! We might also recognise that the shared or interpersonal breath is a vital yet subtle part of human connection that isn't quite the same on a screen or phone. This is a live and pressing topic when care home residents are not allowed to share the intimacy of a loved one's breath, which cannot be felt through a plastic screen.

Breath is not only the foundation of our individual lived experience, it is the building block of relational experience. And we miss that now when dancing, laughing, singing, worshipping and shouting together has become a restricted and potentially dangerous activity.

During my time as a music therapist working in palliative care settings with people towards the end of life (pre-COVID-19), I found that tuning into and regulating the shared breath-space helped patients who were in pain, breathless and anxious. By simply noticing my own breath rhythm, depth, timbre and shape, I get a sense of what is happening on a visceral level; what I am feeling, hearing, sensing in the room for the patient and their family who may be distressed and not know what to do, how to be useful. In a completely non-verbal way, breathing is a way to anchor and hold what Martin Buber [*Ich unt Du,* 1923] called the "sacred space" – the shared interpersonal space of the dying person and their loved ones.

The depth and effect of just being together, breathing, without "doing" lies in the primacy of co-breathing within our earliest embodied and relational experiences. When we breathe together, just as the baby does at the mother's breast, quite naturally we attune to one-another, co-regulating not only our breathing and heart rate, but at the same time our affective experience (emotions). This re-enactment of a deep resonant, pre-verbal experience has enormous power to help people who are frightened feel safe, and when they feel safe, they find their bodily symptoms (the soma) are less urgent. I have seen this time and again clinically in the hospice, and also with both my own parents during the dying phase.

When my Dad died from cancer in a hospice where I was working in 2016, I was already interested in breathing textures, sounds and rhythms, and their link to affective and relational experience. Around this time, I began working with the Wellcome-funded *Life of Breath* project (an interdisciplinary project based at the Universities of Durham and Bristol exploring breathing and breathlessness), and was asked by our collaborators at Breathe Oxford to put together something creative about breath for a public event.

This was my first attempt at a soundscape; the idea was to create a 'breath-voice collage' to illustrate how I felt about the relationship between breathing and emotion. I started by recording an 'anchor' breath, which would act as a metronome throughout the piece. This was the sound of a heartbeat timed to

a 'coherent' breath at six breaths per minute. This slow, relaxed breath with an equal focus on inhale to exhale is commonly used by meditators and yoga practitioners, and has been shown to help people recover from trauma and anxiety disorders, and to relieve physical and psychological pain.

I then interwove recordings I had saved on my phone over the years; my children as babies, their sleeping breaths, an old recording of my partner and I singing *Silent Night* to get our child to sleep (he had to have the same song, in duet, with a ukulele for several years!) I also recorded a patient with chronic obstructive pulmonary disease (COPD) sitting with me in therapy and his words describing how he felt about his breathlessness. Lastly, I used a recording of my father's sleeping breath during his final days in the hospice where he lay dying with metastatic prostate cancer. During that time, the sound of his breath was extremely important, precious and fragile because I knew it would end. In the liminal phase between life and death I sang to him, first breathing together, then voicing the breath to create a sort of lullaby or – towards the end – a "lullament" (lullaby/lament). Dad's childhood was spent in Scotland, and I often found the melodies I sang becoming Celtic folk songs. The Skye Boat Song was one of his favourites….

This soundscape was created three years before Covid-19 and has lingered on a back-shelf podcast at the University of Oxford since then. In these breath-heightened times, it felt right to give it a new lease of life. I hope if you listen you will – like me – appreciate your own breath and that of those you love.

*Listen to the soundscape with headphones for best effect. ***Emotional Trigger Warning – this podcast might provoke feelings of sadness or grief****

March 2021

Bringing Breathlessness into View

by Ann Hutchinson.

What is it like to feel breathless each day?

More than being unable to catch your breath for a few moments after say running for a bus…

Like breathing through material stuffed in your mouth

Like having your head in the clouds

Suffocating, smothering, stifling

Breathlessness is a near constant companion, a thorn in your side. More than a physical sensation of having difficulty breathing: a whole-person experience, an interpersonal experience, a spatial encounter.

You become very aware of your bodily sensations and your thoughts, feelings and actions…

Alone, worried, frightened, panicked, claustrophobic, limited

You become aware of places around you and slight slopes become hills, stairs scare you…

You become aware of others’ responses to you and your breathlessness…

Misunderstood, invisible, dependent, lost “But you look alright”

And how does this all sum together?

Depressed, overwhelmed, self-conscious, reliant, unnoticed

And how is it to be breathless now in the time of COVID-19?

What new words describe your experience now?

Confined, vulnerable, shielded, isolated

How do healthcare spaces feel now? How does it feel to think about needing to go to hospital?

Places to be avoided if at all possible? Or places of safety?

Which fear is greater? The fear of going to the hospital and possibly catching COVID-19 or the fear of breathlessness overwhelming you as you struggle at home?

This exploration of how it feels to be breathless draws on the research of Ann Hutchinson and the ‘Bringing Breathlessness into View’ exhibition.
For advice on how to manage breathlessness read the Guide to living well with breathlessness.

May 2021

Dying a Death of One’s Own

by Miranda Tuckett.

I would like to thank the individuals who shared their time and their stories with me. Names have been changed.

When I first met members of a British right-to-die group in 2019, I asked what had motivated them to join the organisation. Some had had the experience of accompanying a family member to Switzerland where British citizens have access to euthanasia, others were driven by a desire to change the law, and others still were searching for a way of dying which they felt was unattainable in current British hospitals or care homes. Unexpectedly, touch became a central aspect of many of these conversations. Whether it was the comforting hand squeeze offered to a dying sister, the gentle touch of a foreign doctor, or the tactless way that home-health care workers carried out a risk assessment, tactility emerged as a primary concern. Of course, tact is embroiled in expectations of class and Englishness as much as it is in affect and relationality. To be tactful is to be well brought up and to know one’s boundaries: what is and isn’t the correct mode of comportment. To be overly touchy-feely is generally not expected, or wanted, in British society – even in medical settings, the role of the physical examination has been diminished considerably. So touch was a slightly surprising point of contact for these interviews.

An opposition was being created in the narratives I was told between a kind of care which was *desired* and one which had been witnessed for dying parents or friends and relatives – a kind of care which was referred to as inappropriate, or even, at times, torturous. Individual nurses or care workers were singled out as kind or helpful, however the general experience of dying in Britain was perceived as exhausting, cruel, and impersonal. One woman, Elizabeth, recollected the isolation and confusion she had felt when her mother was dying. She had been left to advocate for her mum and coordinate the local care services which were offered. Rather than experiencing this “support” as caring, the goal-setting style of targets which set “progress oriented” objectives was felt to be a managerial, bureaucratic ticking of boxes. “I mean” she said to me with evident frustration, “the woman was *dying*”. As if she, Elizabeth, were the only one to notice.

Such a feeling of insensitive support contributes to a sort of anaesthetic care. Anaesthetic care, as I am imagining the term, is the combination of a particular relationship between doctor and patient, combined with an experience of profound disembodiment. The anesthetisation of care is exemplified in the tactless care that Elizabeth describes or by an image we are all familiar with: the anesthetised patient. It is not a form of abandonment, but rather a desensitisation of care. Anaesthesia has the effect of arresting pain and numbing the patient’s body. The drug was first used in Boston in 1856 by Dr John Warren. As was the fashion in those days, the operating theatre was full for the drug’s debut. The spectacle of surgery now included an uncanny corpse-like patient. Pain and consciousness were managed to such an extent that the surgeon no longer had to concern themselves with showing empathy to the patient and could focus entirely on the task at hand—saving life (Buck-Morss 1992). Indeed, training doctors to see bodies as parts to be mended as opposed to as persons, is a process that medical students must actively learn and struggle with (Good, 1993).

By asking for assisted dying or suicide, individuals I spoke with were looking to be held in their last moments. In the words of one woman, to be “allowed to go kindly”. This emphasis on permission and guidance seemed at odds with the trope of the autonomous, control-obsessed right-to-die campaigner. “It’s **My** death **My** decision” I was repeatedly told – and I started to wonder if the ownership implied by the possessive pronoun had less to do with ownership as we understand it in neoliberal terms and had more to do with a desire to counter a feeling of dispossession that people expected to experience were they to become “dying patients”. A desire to inscribe themselves into their own dying and be materially present and in touch with loved ones and doctors. Perhaps owning one’s death has less to do with mastery and control, and is, in fact, a wish for an engaging and sensitive response to dying.

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Wake Up and Smell the Roses

by Shamhain Scannell.

When you think about your five core senses, you probably think of them in equal measure, each of them being just as important as each other. Well, I used to disagree. I have had anosmia (loss or the changing of your sense of smell) since I can remember, on account of my nose collapsing in on itself as a baby, and it doesn't appear to have affected me too negatively. Of course there are scenarios where it would have been helpful, for example the other day at work, my manager jumped out of her chair and suddenly exclaimed "something's burning", before swiftly walking towards an area of the store where she was certain the odour had originated. Then sure enough, two other colleagues started to smell it too. And before long, if you happen to have peered into our store, you would have seen three people being led on a mission by their noses, and one person stood sheepishly in the middle of the store, trying to remember the fire drill procedure. In the end, the smell sort of faded away and the search was put to a stop ... but that didn't make the threat any less worrying. There still could have been a fire ... and I wouldn't have known. It turns out that smell is important.

Smell is also pretty useful in terms of tasting; smell makes up about 80% of taste. I've actually got a pretty good range in terms of taste. I only really notice that I can't taste something when it comes to more subtle flavours like floral or herbal ones (flavoured sweeties are lost on me). Again, that was something that didn't use to bother me, but I currently work in a luxury food shop. It's a bit embarrassing to tell customers that all of our flavoured teas (of which there are a lot) taste akin to a glass of water with a drop of orange cordial in it.

The sense of smell wasn't so important when I was young and I was only responsible for me, myself, and I. But now I'm in my mid twenties ... and it would be nice to tell for myself whether my shirt smells of B.O., or whether it can withstand another wear before chucking it in the wash. And given that I've just had nine surgeries to open up my nose to allow me to breathe through it, now seems like a good point to start trying to smell through it too.

Now how would a person go about learning to smell, you may be wondering. Well to start off with, it's like learning anything; it takes time and practice. So to 'practise' we need a controlled environment that can stay consistent through the learning process. This is where we bring in the smelling kit. Smelling kits can be bought online, or made at home using these items:

4 amber glass jars
4 cotton pads
4 essential oils (the recommended ones are rose, lemon, clove, and eucalyptus).

In each jar goes one cotton pad, and a small amount of an essential oil. Each jar is then meant to be smelt for at least 30 seconds every morning and every night, for at least 4 months.

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Smell training like this is meant to help those who have had a change in their ability to smell, whether it's just weaker than before, or the sense of smell is gone completely. In the month before I started doing the smell training officially, I had hints of 'smell'. For example, walking into a coffee shop was like walking through a curtain of coffeesmelling smoke, but then as soon as I came out the other side, it was gone. It would last all of 5 to 10 seconds, and it was very very faint ... but it was there. Then I would get it again when my Grandad was making burgers, or when I was cooking porridge ... all very quick and faint ... but something was definitely happening. I started the smell training with high hopes, as the essential oils are all meant to be fairly fragrant ones.

Rose = 0/5
Lemon = 3/5
Clove = 2/5
Eucalyptus = 4/5

So 'rose' did nothing for me. Not even a hint. 'Lemon' was one of those ones that I had smelt previously for those few precious seconds when I first started grating it to make cookies; I would sometimes be able to smell it in the jar, and sometimes not. 'Clove' and 'eucalyptus' are very similar in that you don't only smell them with your nose...you feel them in your mouth and your chest. Clove gave me that a little bit, and eucalyptus gave me that so much that I would have to close my eyes to try and smell it. Overall I quite enjoyed having my training jars next to my bed and incorporating them into my morning and nighttime routines (I'm using past tense here, because I haven't been doing the smell training since my recent surgery on my nose, just over a month ago, but I will get back at it!). Smell training is not a quick fix though. I had been doing it for about 3 months when I had the surgery, and the change has not been very noticeable (let's bear in mind that I'm trying to go from nothing to something, so it'll be harder and take longer).

I remain hopeful. I would like to be able to smell ... to unlock memories, places, and people with a whiff. I want to be able to recognise food with my nose, before my eyes. I want to be able to feel safe in a building on my own, and not have to rely on an electronic box in the ceiling to tell me if there's smoke nearby. And I just want to join in ... to know what 'smell' really is. Because I've heard it's pretty great.

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