
## Panel ABSTRACT

### Panel 09: Sustaining life in debilitated environments: expanding ideas of contagion, chronicity and care in the "age of disability"

**Organizer:** Júlia Fernandez, Rosamund Greiner

**Abstract:** The conditions of the anthropocene, neoliberal governance and colonial age produce diverse forms of injury, ill health and impairment (Segata et al., 2023), marking the ongoing debilitation of certain populations, which Berlant has described as "slow death" (2007, see also Puar, 2017). Such conditions concentrate vulnerabilities along existing lines of oppression, producing "embodied social inequalities with transgenerational potential" (Montesi and Calestani, 2021: 1). Taking up this idea, we call for a consideration of chronicity and impairment as socially transmitted, and how entanglements of kinship and care come to be implicated in these processes. This is exemplified in the concept of "dis/abling care" (Williamson, Engel and Fietz, 2023), which articulates the debilitating nature of gendered care work under conditions of chronic precarity (see also Han, 2012; Mattingly, 2014; Ballesteros, 2021). Further to this, the notion of "interembodiment" of chronic illness within relationships of care (Bunkley, 2022) troubles the Western, patriarchal epistemology and ontology of sovereign subjects with bounded, discrete bodies, prompting instead to think of illness and disability as defining conditions of our relational, interdependent existence (see Butler, 2016). Finally, expanding the idea of embodied vulnerabilities, Taylor's conceptualisation of "disabled ecologies" (2021, 2024), or Dewachi's "wounding ecologies" (2021) invite a fuller consideration of the interconnection of bodily injury beyond the human. We invite papers that contribute to an expansive understanding of the transmissibility and chronicity of illness and disability within debilitated infrastructures and environments, and that attend to how biosocial relations of vulnerability and care manifest under those conditions.

## SESSION SCHEDULE

**19.09.2025 | Slot 3 & 4| 4-0-6**

*Samiksha Bhan: Dis/abling Cure: Medical humanitarianism, therapeutic markets and the failure of proximate care for thalassemia-affected in India*

*Emma Bunkley: Interembodiment, Inheritance, and Intergenerational Health*

*Maria Elisa Dainelli: The contagion of suicide: Good and bad death in ethnoclinical context.*

*Marcela González-Agüero, Valentina Turén, Angélica Farías-Cancino: Appealing for the right to live: Care, precarity and the risk of a slow death for Chilean children and young people with SMA*

*Daniela Jacob Pinto: Feeling each other's pain: injury and healing amongst citizens mutilated in protests in present day France*

*Narod Seroujian: Debilitated Bodies, Relational Wounds: (Un)stitching Care in Lebanon*

*Ramsha Usman: Always Injured, Never Disabled: Workers Health in Sustainable Ecologies of Production*

*Lindsay Vogt: Others in the Self: (Inter)corporeality and Affective Entanglement between Mother, Daughter, and Home in End-of-Life Care*

## SESSION PAPERS

### Dis/abling Cure: Medical humanitarianism, therapeutic markets and the failure of proximate care for thalassemia-affected in India

*Samiksha Bhan*

The expanding diagnosis of rare diseases and chronic illnesses has led to new therapeutic markets in the global South. Catering to some of the most populous and poorest countries, a new segment of transnational experts has emerged while blurring the lines between medical humanitarianism and international development. In this presentation, I draw from 13 months of doctoral fieldwork on provision of the curative bone marrow transplant for thalassemia-affected children in India, suffering from a debilitating genetic blood disorder. Following disability studies scholars, I complicate the hope attached to new therapies by arguing that cure takes precedence over care under historically produced conditions, enabling therapeutic markets to flourish at the cost of proximate relationalities of care and support. In the case of thalassemia, transnational brokering of affordable bone marrow transplants is directly related to the failure of locally administered blood banks to provide transfusion services for patients to maintain their quality of life. While medical anthropologists have extensively followed the double bind of care as an exploitative and life-sustaining force, I speculate if conceptualising a 'dis/abling cure' might illuminate the debilitating ways in which cure becomes available and presented as the only choice at the limits of care.

### Interembodiment, Inheritance, and Intergenerational Health

*Emma Bunkley*

This talk discusses the concept of interembodiment, animated bodily entanglements between people, to illustrate the shared sense of illness that transgresses discrete biological bodies. Drawing on 15 months of ethnographic research in Senegal, West Africa, this article expands common understandings of inheritance and intergenerational health by exploring how women caring for others with metabolic disorders come to interembody the afflicted’s symptoms, regardless of their own diagnostic status. These

experiences trouble the clear distinction between communicability and noncommunicability and disrupt Western understandings of distinct, unshared biologies. Through the concept of interembodiment, we can see how noncommunicable diseases come to be communicated. Interembodiment helps explain aspects of intergenerational health between mothers and daughters and allows for broader understandings that encompass multiple biologies. Shifting the focus of health and illness from the individual to multiple interembodied biologies allows for a more nuanced understanding of disease and disease transmission, which could enable global health and public health programs to better address noncommunicable diseases around the world.

## The contagion of suicide: Good and bad death in ethnoclinical context.

*Maria Elisa Dainelli*

My contribution stems from three years research work, as an anthropologist, in the field of ethnoclinical mediation in the Region of Tuscany. The case I want to examine concerns the “contagion of suicide” as element of pathologisation and discord in a group of Nigerian people housed in a CAS (Centro di Accoglienza Straordinaria). Following the suicide of one of their compatriots, they had to deal with the oppression of their grieving process and with a silence imposed by CAS organization to quell discontent and riots among users.
The ethnoclinical team was therefore faced with an extremely complex case, in which the triggering event represented an example of ‘theoretical mistreatment’ (Sironi, 2010) of a mournful event. One might add, in fact, that the reaction of the CAS managers to the users' turmoil and demands is to be ascribed within a process of “deculturation” that F. Sironi (2010) describes in her work.
The contribution will therefore focus, at first, on the description of the ethnographic case, then concentrating on the analysis of the concept of ‘bad death’ and how this can influence, even in its pathological drifts, the life of those who remain. In the second step, the host context will be analyzed as a site of pathology production (Perazzo, 2022). Events can be ascribed to what R. Beneduce (2004) describes as ‘ethnographies of the third kind’. They are composed of critical, fringe scenarios in which unbalanced power relations describe conditions of humiliation and violence suffered both in life and death.

## Appealing for the right to live: Care, precarity and the risk of a slow death for Chilean children and young people with SMA

*Marcela González-Agüero, Valentina Turén, Angélica Farías-Cancino*

Spinal Muscular Atrophy (SMA) is a rare genetic disease that affects individuals’ muscle strength. As the disease progresses, it can lead to early death or serious disability. Children and young people with this condition require ongoing permanent care. Prior to 2016, there were no pharmaceutical treatments for SMA, which reduced survival rates and individuals' quality of life. The FDA approval of three high-cost drugs in a three-year period generated public policy developments while patients demanded a prescription with their clinicians. As the treatment is not covered in the Chilean public system, access to these drugs has been achieved through the judicialization of the right to live. In this paper we argue that the experience of having a rare and dis/abling condition is intertwined with the role of the state in the provision of care and the dynamics of therapeutic markets, as well as with organisational dis/abling strategies of care and

more private, relational moments of care. Through 12 months of fieldwork in two large cities, we reflect upon the tension between patients and organisations' strategies to appeal for the right to live and State-led arguments to reject their petitions, while still maintaining their commitment to care for individuals. In this process, the possibility of a slow death is ever-present. Amid chronicity and disability, the life trajectories of our informants allow us to bring to the fore the structural violence involved in processes of judicialization, which is in permanent tension with their efforts to co-create scenes of hope and care.

## Feeling each other's pain: injury and healing amongst citizens mutilated in protests in present day France

*Daniela Jacob Pinto*

During the last decades the French welfare State has been progressively subjected to neoliberal reform, which has negatively impacted the livelihoods of working- and middle-class citizens. The worsening of living conditions has bolstered social movements (like Nuit Debout in 2016, Yellow Vests in 2018-2019), which have been violently contained by police forces, leaving several citizens injured and mutilated. This presentation is based on 22 months of ethnography amongst mutilated citizens, and their networks of support and care. I followed them through court hearings, political organizing for truth and justice, and their daily lives, also interviewing lawyers, social workers and medical professionals involved with them. I observed that these mutilations are embedded within wider systems of social inequality, chronically impacting the livelihoods of those concerned. Moreover, pain and stigma of mutilation are interembodied (Bunkley), also affecting family and peers. Therefore injury is collectively experienced and repaired. Nevertheless, being mutilated has created a particular sensibility in my interlocutors: they assert they feel in their bodies the pain of others who suffer police violence. Therefore their political organizing has the purpose of halting police violence in general. Injury—in this case—is mobilized to stop cycles of violence (Ralph). In a context where our lives are mutilated by capitalist society (Adorno), what distinguishes my interlocutors from others is that they are conscious that they have an injury that has a social and political origin. Can the mutilated help us imagine a politics where recognizing our own socially inflicted pain becomes the basis for collective healing?

## Debilitated Bodies, Relational Wounds: (Un)stitching Care in Lebanon

*Narod Seroujian*

Wounds in debilitated locales extend beyond the individual injured body and become entangled in broader infrastructures of neglect (Livingston, 2013), indexing ongoing processes of debility marked by "geographies of violence" (Dewachi, 2015). In this paper, I unpack wounds in Lebanon as affective, social, and political entities through a material-semiotic framework, building on Dewachi's call for the wound as a method (2021).

My analyses draw on previous ethnographic research conducted in the aftermath of the Beirut port explosion of August 4, 2020, and recent observations following the digital circulation of photographs depicting bodies injured by the Israeli pager attacks (17 September 2024) in Lebanon. I argue that care in "wounding ecologies" (Dewachi, 2021) takes multiple, often frictional forms, oscillating between concealment and display. I then trace how friends, lovers, comrades, mothers, reconstructive surgeons,

ophthalmologists, and photographers all venture into the lifeworlds of wounds, embodying vulnerability and blurring the separation between injured and non-injured bodies. Finally, I showcase how wounds serve not only as tools of substantiation (Dawney, 2019) for toxic governance and colonial interventions empowered by a sovereign "right to maim" (Puar, 2017) but also mobilize accusations and resistance. In a state of chronic collapse, wounds in Lebanon challenge debilitated environments, contest political forgetting, and assert life and visibility in the face of debility and abandonment.

Engaging with the panel's inquiries, my paper contributes to the anthropology of wounding and debility. I demonstrate how, through everyday caring practices and relations, woundedness becomes a relational, "interembodied" condition within chronically debilitated infrastructures.

## Always Injured, Never Disabled: Workers Health in Sustainable Ecologies of Production

*Ramsha Usman*

Scholars of late industrialism have demonstrated how toxicity and chronic conditions emerge from industrial leakage and disrepair. I trace the promises of sustainable growth in the wake of industrial disrepair in Pakistan and how the imagined circularity within sustainability practices reorders the already fraught binary of accidental- chronic within workers' health. Sustainable industrial systems have sought to include infrastructures of care like the local welfare system creating "sustainable ecologies of production". By including infrastructures of care, industrial systems both produce workplace accidents and injuries while providing care for those injuries, with the promise of worker retention. This paper focuses on the care processes that take place after an accidental injury to highlight how one worker remained between the debilitation of industrial work and attendant care processes, with a partially healed wound treated each time just enough to return him to work. The recursive movement between work and care destabilizes the boundaries between accidental injuries and chronic wounds and reveals how injuries neither heal nor get the official status of or compensation for disability within sustainable ecologies of production. The imagined circularity of sustainability is transposed onto bodies imagining workers' health as a regenerative resource, resulting in cyclical wounding and partial healing. Including workers' accidental injuries within existing questions of toxicity and chronicity, I destabilize the "accidental", highlighting it as a cyclical process of wounding and healing produced and sustained through circular industrial imaginaries.

## Others in the Self: (Inter)corporeality and Affective Entanglement between Mother, Daughter, and Home in End-of-Life Care

*Lindsay Vogt*

This piece is a daughterly-anthropological inquiry into the nature of the (inter)corporeal self, other, and the porous boundaries and intrusions between them in the shadow of

terminal illness and the labors of care it necessitates. Utilizing a combination of autoethnographic and ethnographic methods in a situation of care for a terminally ill parent (2022 to the present), I examine the material extensions and deposits of the body and their exchanges, between individuals (daughter/caregiver and mother/cancer patient), the physical environment of care (home), and across several generations of one matriline, interrogating not only the affective and substantial reverberations and recombinations between them but the idea of the (un)bounded nature of the individual itself. As terminal illness and the lingering possibility of death calls daughter-caregivers home for age-old womanly work, reconstituting the family socially, it beckons further questions about the embodied, physical continuities (entrapments?) of familial relationality and transmission. The mother-daughter is an embodied relation, in part, because a daughter is a materialization of her parents made vital, but care work itself is corporeally consequential and the very settings of care, too, are constitutive of the affective, and indeed corporeal-material, relationality that engender the mother-daughter relationship and daughterly caregiving work at the end of life. Autoethnography, which understands the personal as political and utilizes the self as a primary locus of sociocultural analysis, enables unique ethnographic access to intimate family settings and dynamics over extended periods of time.