Roundtable ABSTRACT

Roundtable 01: Material certainties: critical reflections on the future of ethnographic research in disease and pain

Organizer: Jose Manuel Allard Serrano, Sofia Ceresuela Del Valle, Rodrigo Diaz-Canio

Abstract: Phenomena such as the pandemic, climate change, political conflicts, and the economic crisis are forcing us to rethink our life models, challenging the practices and relationships that have shaped our socio-cultural structures. In response, anthropology calls for interdisciplinary approaches that go beyond conventional methods to drive meaningful change. To do this, we must engage with the contested politics of an uncertain world. The intersection of design and anthropology emerges as a key ally in this process. Medical anthropology offers critical insights into how societies manage suffering and pain, especially in terminal illness, and provides perspectives on how we can reimagine these experiences more inclusively and compassionately. This collaboration has the potential to create new environments, tools, and solutions that transform care, positioning design as essential in managing pain and suffering.
This roundtable invites ethnographers to reflect on the various materialities in the field that help cope with the illness and pain. In particular, we will explore how medical teams, patients and their support circle, in precarious environments, ingeniously manage to cope with the pain and emerging imaginaries of the failures, inequalities, and discriminations inherent in healthcare systems. We want to think about the future of ethnographic practice in disease and pain research, exploring how emerging materialities in palliative care can become self-managed certainties. We aim to discuss how these materialities challenge the limitations of biomedical models and offer opportunities to speculate on materiality as a certainty capable of exposing current limitations and imagining less painful futures.

SESSION SCHEDULE

17.09.2025 | Slot 4| 2-0-4

Enka Blanchard: Pain and utilitarianism in disability studies

Livia Fernandes, Cheryl Davies, Jean Hay-Smith, Chrystal Jaye, Hemakumar Devan:

INSIGHTS FROM ETHNOGRAPHIC OBSERVATIONS OF A PAIN SERVICE: HIDDEN MESSAGES IN ENVIRONMENT AND INTERACTIONS

Maria Fernanda Pineda, Antonia Catalan, Maria Vega, Sebastian Castro, Teresita Gutierrez, Vicente Gomez: Towards more effective organ donation systems through design

SESSION PAPERS

Pain and utilitarianism in disability studies

Enka Blanchard

The recent financial and medical crises have pushed to the forefront questions of resource allocations in contexts of limited supply of critical elements, such who gets to use ventilators when a hospital has too many patients. One could expect a natural tension between disability activists (arguing for equal or priority access for the least well-off) and largely shared utilitarian ethics among policy-makers and the population (arguing that the objective is to maximise either lives saved or number of expected years saved). In some Western countries, even the latter option was recently shown to be unrealistic, with covid policies deprioritising disabled lives, even when saving them would be the utilitarian choice. This questions the role of utilitarianism as a central element in disablist policies, and the relevance of its historical critique in disability studies and activism.

This contribution will look at the tension around the problems of materiality and pain in disability studies. Many social justice movements assert the irrelevance of most standard categorisations (e.g., gender, race, orientation) when it comes to life's worth. Although disability activism has long held that disabled lives, including ones lived in permanent pain, are worth living, it has struggled to address the questions of whether they are worth quite as much, especially in a utilitarian framework. This has led to a rejection of such frameworks, which hinders the ability of disability studies to address contemporary questions of policy-making. This could, however; be revisited, if one accepts a radical pride in painful and disabled bodyminds.

INSIGHTS FROM ETHNOGRAPHIC OBSERVATIONS OF A PAIN SERVICE: HIDDEN MESSAGES IN ENVIRONMENT AND INTERACTIONS

Livia Fernandes, Cheryl Davies, Jean Hay-Smith, Chrystal Jaye, Hemakumar Devan

Western epistemology privileges words to convey meaning in health services, evident in posters, leaflets, and self-reported questionnaires. However, meaning can be communicated beyond words. For Māori, mātauranga (knowledge systems) involves relational processes such as storytelling (pūrakau), visual arts, music (waiata), and tikanga (practices). An ethnographic approach was employed to observe interactions in a specialized pain service in Aotearoa New Zealand (July 2024–July 2025), focusing on how chronic pain is explained, discussed, and shaped by the service environment.

Observations included (1) multidisciplinary meetings where the pain team met with Māori with chronic pain and whānau (family), focusing on how pain was accessed, discussed, and addressed; (2) analysis of spaces, places, and people flow (e.g., waiting area, entrance, hallway, decoration). Data included fieldnotes, photographs, and ethnographic reflections. Critical theory and Two-Eyed Seeing informed data analysis, guided by reflexive thematic analysis. By March 2025, seven consultations and three environmental observations were conducted. A key finding suggests hidden messages in the environment. The pain service's complex location—requiring navigation through corridors, lifts, and fire doors—mirrors the complexity of pain aetiology. The sterile setting, cold colors, and minimal adornment reflect a biomedical approach, where objectivity dominates and the person may feel secondary to symptoms. We reflect that understanding pain and navigating the service are equally complex. Critical lenses bring notions of foreign spaces and intersectionality into discussion. Insights from this fieldwork point to the relational and environmental aspects of care that may influence how Māori with chronic pain perceive care.

Towards more effective organ donation systems through design

Maria Fernanda Pineda, Antonia Catalan, Maria Vega, Sebastian Castro, Teresita Gutierrez, Vicente Gomez

This study seeks to understand in depth the needs of transplant patients, based on diseases or critical conditions that affect their organs. Qualitative information was collected through semi-structured interviews with health professionals and photo-elicitation to transplant patients, with the aim of understanding how the current health system works and how it impacts on post-transplant quality of life.

Adaptation to this new condition involves complex processes that require comprehensive medical, emotional and social care. It is essential to consider the patient within their support network to ensure that the transplant is not only successful, but also that their survival is meaningful, autonomous and marked by well-being.

Faced with these complexities, digital systems appear as a key tool to facilitate access to personalized and multidisciplinary treatment, addressing dimensions such as mental health, physical activity, nutrition and personal relationships.

This type of approach not only improves the experience and quality of life of transplant recipients, but also contributes to solving structural challenges in the healthcare system. By facilitating remote follow-up and comprehensive support, it contributes to the decongestion and decentralization of health services, favoring closer, more equitable and sustainable care over time.