Panel ABSTRACT

Panel 19: Entangled temporalities of the experience of “chronic living” with technological devices

Organizer: Agathe Camus, Lucie Dalibert, Valentine Gourinat

Abstract: Disability and chronic illness have become a privileged place for technological intervention. Both are characterized by the deployment of technological devices that aim to mitigate, compensate for, or even prevent and slow down the loss of capacities, as well as alleviate or limit symptoms. In this context, a varied array of technologies that differently act on or intervene in bodies and places are introduced in people’s lives (e.g. insulin pumps, prostheses, dialysis equipment, telecare, etc.).
Regarding this ‘technological care’ (Lancelot & Guchet, 2023), research in STS and medical anthropology has mainly focused on technological use and appropriation, including the difficulties thereof. However vital and essential these technologies may be in sustaining people in daily life, attention has scarcely been paid to their fragility and people’s resulting vulnerability when they malfunction, wear and tear, break and/or thus can no longer be used or have to be adjusted and/or used differently (Oudshoorn, 2020).
These material and existential disruptions and constraints call for inquiring about the entanglements of different temporalities of chronic living (Wahlberg & al., 2021): of bodies adjusting to chronic illness, disability and/or to technological care; of the technologies themselves (from their development to their everyday use, adaptation, malfunctions and maintenance) and the socio-material infrastructures that support them; and of the relations between them. We invite contributions that address technological care and its temporalities in the context of disability and chronic illness.

SESSION SCHEDULE

17.09.2025 | Slot 1 & 2| 4-0-5

SLOT 1 - 9:00-10:30

- Lydie Bichet : Living with Chronic Illness and Technological Devices : DT1 as “Another Pace of Life”

- Gabrielle Hanley-Mott : Function, Fantasy, and Fragility: Imaginaries and Realities of High-Tech Hand Prostheses

- Chenchen Ma : Folding Care Practices: Temporality and Prosthetic Rehabilitation

- Mathilde Lancelot & Sonia Desmoulin : Living with or accompanying chronic illness and technological care: different logics of temporal entanglements

SLOT 2 - 11:00-12:30

- Enka Blanchard : At the mercy of a potentiometer : device repairability and disabled temporalities

- Agathe Camus, Lucie Dalibert & Valentine Gourinat : Technological assemblages and bodily intimacies: An exploration of the chronic experiences of diabetics with multimorbidity

- Sally Cross : Forecasting the fog: navigating crip time with health-tracking apps

- Anna Christina Maukner & Ellen Algera : "I realised relatively quickly that it really stressed me out": Temporalities in self-tracking with long COVID

SESSION PAPERS

Living with Chronic Illness and Technological Devices: DT1 as "Another Pace of Life"

Lydie Bichet

The onset of illness disrupts our relationship with the world (Merleau-Ponty 1945) and undermines the taken-for-granted sense of inhabiting a smoothly functioning body (Bury 1982, Charmaz 1995, Corbin Strauss 1988). Type 1 diabetes - a chronic illness that often begins in childhood - is emblematic of such disruption. It accentuates the body's unpredictability at a age when mastery over the body is expected to increase. Drawing on ethnographic fieldwork conducted with children (doctoral research, 2021) and young people (PASMAC research) living with T1D, this presentation explores the temporalities entangled in the experience of chronic illness and technological care.
It examines the experience of a "disordered" body and the specific temporality imposed by the illness – one that deviates from collective rhythms to align with the fluctuations of organic processes. Technological devices (glucose sensors, insulin pumps…) designed to compensate for pancreatic function may themselves introduce disruptions into the course of everyday life, even as young people strive to "live like everyone else".
As they assert, they live a "normal" life', "like others" - but not on the same temporality. This claimed normality entails continuous efforts in being adapted to the environment by adapting the environment itself, particularly in everyday and family life. The domestication of the illness involves socio-material, spatial, and temporal adjustments, the latter being marked by anticipation and regularity, as an attempt to create order and stability in the environment to contain physiological instability. In this sense, the illness constitute a new order, another pace of life (Canguilhem 1966).

At the mercy of a potentiometer: device repairability and disabled temporalities

Enka Blanchard

The increased survival of both elderly populations and younger lives who would historically have been ended by childhood illnesses has led to a higher share of people whose lives are dependent on machines, either to live socially or simply to survive. This contribution will look at the specific case of mobility scooters, which lie at the intersection of medical and commercial devices.

Existing devices can become a double-edged sword. They are highly attractive as they are generally sold at a lower price than many alternatives (such as power wheelchairs where the prices are sometimes inflated through public subsidies), although this pricing hides massive price margins linked to monopoly power. They also suffer from reliability issues which leave many users waiting for repairs, worsened by supply chain issues. Far from designing for repairability, many technical aspects are instead meant to lock both users and vendors into specific systems. Ideally, one would see solutions from open hardware communities aimed towards having more fixable designs and less dependency, but they face many hurdles around both intellectual property and safety legislation. Some socialised systems based on public subsidies also exist but they are still rare.

This is disabling and puts central elements of disabled lives at the mercy of bad luck. Their temporalities are hence affected through both arbitrary failures which can prevent any mobility for extended durations and the time expenses of trying to plan and compensate in advance, which will be the central focus of the talk.

Technological assemblages and bodily intimacies: An exploration of the chronic experiences of diabetics with multimorbidity

Agathe Camus, Valentine Gourinat, Lucie Dalibert

In the care trajectories of diabetics with multimorbidity, technological devices of different kinds and with different modes of use may be required to enable people to take care of themselves (insulin pumps, artificial pancreas), to move around (diabetic shoe, limb prosthesis) or to continue to live and take care of themselves at home (home dialysis machine). However, in such complex chronic conditions, friction, overlap and even incompatibility or impediments may arise between the different technologies, care infrastructures and environments required to deal with a specific problem, which can ultimately disrupt the various forms of intimacy that have developed between bodies and technologies.

In the context of diabetes, this contribution aims to analyse the complex assemblages, arrangements and entanglements that exist between bodies, technologies and environments, resituating them in the complex and evolving spatialities and temporalities of multimorbid chronic experience. We propose to apprehend them from the concepts of intimacy (Dalibert, 2014, 2016; Oudshoorn, 2016; Forlano, 2017) and crip space/time (Kafer, 2013; Price, 2024). In this endeavour, we will particularly attend to the way chronicity is transformed and experienced. To do so, we will rely upon ongoing ethnographic fieldwork (realised in France) with people living with diabetes (DT1 & DT2) and its complications (chronic kidney failure; amputation; visual complications).

Forecasting the fog: navigating crip time with health-tracking apps

Sally Cross

Smartphone apps and wearable technologies are increasingly entangled in the research and management of chronic illnesses. For people with uncertain experiences of pain and energy limitation, these digital technologies promise to reshape the temporalities of chronic living by simplifying the pacing of activities and forecasting illness flare-ups. 'Digital biomarkers' are assembled from recordings of pulse rate and activity and mapped onto patients' self-reported symptoms. Proponents of these technologies argue that they provide an objective measure of subjective experiences of illness, allowing for a more visible and less uncertain future for people experiencing constellations of fluctuating and disabling symptoms. This presentation relates the development and use of technologies that track symptoms and activity to ideas of crip time, which challenge normative temporalities by valorising slowness and rest. This analysis draws from ethnographic work with researchers, clinicians and patients with and/or working on ME/CFS and fibromyalgia in the United Kingdom. I ask, can health-tracking apps help people to navigate crip time? I question if these technologies support people with chronic illnesses to tune into the ebb and flow of their symptoms, recognise patterns, and prepare for rainy days. Or, if health-tracking apps constrain the ways disabled people creatively engage with time by encouraging them to maximise their limited resources of health and productivity.

Function, Fantasy, and Fragility: Imaginaries and Realities of High-Tech Hand Prostheses

Gabrielle Hanley-Mott

High-tech hand prostheses occupy a powerful place in the public imagination, often framed by nondisabled media and industry as cutting-edge solutions to limb loss. Drawing on interviews with upper-limb prosthesis users in the United States and participant observation at prosthetics industry conferences, this paper interrogates the disjuncture between the promotional narratives surrounding advanced prosthetic devices and users' temporal and affective experiences of disability. Despite being heralded as the future of prosthetic care, high-tech hand-mimicking prostheses are frequently fragile — prone to breakdowns, high maintenance demands, and prohibitively expensive repairs — generating new forms of uncertainty and dependency. In contrast, low-tech tools, often overlooked in mainstream narratives, offer reliability and embodied familiarity. This paper examines how users navigate, compare, and assign value to both high-tech and low-tech prosthetic tools. I argue that high-tech prostheses do not simply serve functional purposes but also shape imaginaries around time, technological progress, and the perceived "correction" of disability. By foregrounding the tensions between technological promise and material fragility, I argue that high-tech prostheses shape users' expectations and temporal orientations — creating an imaginary that alters their perceptions and value of time and obscuring the embodied utility of low-tech alternatives.

Living with or accompanying chronic illness and technological care: different logics of temporal entanglements

Mathilde Lancelot, Sonia Desmoulin

The concept of “technological care” (Lancelot & Guchet, 2023) has been proposed to describe the indissociability of care and technology in contemporary medicine. However, asserting the interdependence rather than opposition between humans and objects, know-how and skills, cure and care, does not mean, of course, that these relationships do not generate or are not accompanied by tensions. These tensions may be interestingly explored through the under-addressed issue of their temporal entanglements. For example, in chronic illnesses, different temporalities coexist and are interwoven: those of the patient’s lived experience, those of the technological devices and associated maintenance or adjustments, those of the medical agenda or of clinical point of view on the disease and its constraints, those of the administrative and legal system, those of the social infrastructures...We propose here to question various tensions through this question of temporal entanglements in two chronic situations using various kind of medical technologies: Parkinson's disease and multiple sclerosis, two neurodegenerative diseases that affect people who are mainly active and for whom a projection into the future is required. How does technological care reveal shifted expectations related to different temporalities in these chronic conditions and/or disabilities? In two voices (philosophy and law) as part of two funded research projects in progress, we will work on the hypothesis of an entanglement between prolonged and projected lives revealed buy technological care.

Folding Care Practices: Temporality and Prosthetic Rehabilitation

Chenchen Ma

Drawing on ethnographic fieldwork conducted in a prosthetic care centre in Shandong, China, this research examines how patients and prosthetists navigate the dynamic process of bodily change throughout the rehabilitation journey. Through case studies involving medical care practices concerning amputation surgery, bodily pain, and prosthetic adjustments, the article explores how individuals interact with multiple temporalities—past experiences, present needs, and future anticipations—within everyday care practices. Using the concept of “folding” and its topological meaning, I offer a novel framework for understanding time in care work, positioning it not as a linear process but as a continual negotiation shaped by the interaction of different temporalities. This research advocates for a shift in perspective from isolated moments of care to a broader understanding of the care process that spans multiple stages and institutions, with ongoing adjustments to both bodies and technologies over time.

"I realised relatively quickly that it really stressed me out": Temporalities in self-

tracking with long COVID

Anna Christina Maukner, Ellen Algera

For many people living with Long COVID (PWLC), self-tracking has become a valuable tool in managing their chronic illness. This study investigates the temporalities of self-tracking practices and how PWLC negotiate the data generated through self-tracking technologies. Based on 33 semi-structured interviews with PWLC in the Netherlands, Austria and Switzerland, we found that PWLC gain useful insights into their condition by recognizing patterns and identifying limits, triggers, and effective interventions. The research highlights the multi-layered temporalities that PWLC experience: short-term patterns (over hours or days) that help identify immediate triggers, and longer-term patterns (over weeks or months) that inform broader health management. Yet, self-tracking may also negatively influence the subjective illness experience, exacerbating stress and anxiety. Therefore, engagement with self-tracking technologies changes over time as illness management evolves and PWLC increasingly question and negotiate tracking data the longer they practice self-tracking. By focusing on how PWLC adjust to their illness and the technologies they use, this paper situates self-tracking within the broader context of technological care (Lancelot & Guchet, 2023) and the fragility of these practices. It also addresses how PWLC interact with the socio-material infrastructures that support their tracking, revealing how technological care evolves and sometimes creates new vulnerabilities, thus highlighting the complex interplay between bodies, technology, and care.