
This is an electronic reprint of the original article.
This reprint may differ from the original in pagination and typographic detail.

Renedo Illarregi, Erika

Experiencing emergency services as a PhD student during the pandemic: an autoethnography of a holistic breakdown

Published in:
Design for Health

DOI:
[10.1080/24735132.2023.2275490](https://doi.org/10.1080/24735132.2023.2275490)

Published: 09/12/2023

Document Version
Publisher's PDF, also known as Version of record

Published under the following license:
CC BY

Please cite the original version:
Renedo Illarregi, E. (2023). Experiencing emergency services as a PhD student during the pandemic: an autoethnography of a holistic breakdown. *Design for Health*, 7(3), 430-439.
<https://doi.org/10.1080/24735132.2023.2275490>

This material is protected by copyright and other intellectual property rights, and duplication or sale of all or part of any of the repository collections is not permitted, except that material may be duplicated by you for your research use or educational purposes in electronic or print form. You must obtain permission for any other use. Electronic or print copies may not be offered, whether for sale or otherwise to anyone who is not an authorised user.

Experiencing emergency services as a PhD student during the pandemic: an autoethnography of a holistic breakdown

Erika Renedo Illarregi

To cite this article: Erika Renedo Illarregi (2023) Experiencing emergency services as a PhD student during the pandemic: an autoethnography of a holistic breakdown, Design for Health, 7:3, 430-439, DOI: [10.1080/24735132.2023.2275490](https://doi.org/10.1080/24735132.2023.2275490)

To link to this article: <https://doi.org/10.1080/24735132.2023.2275490>



© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 09 Dec 2023.



Submit your article to this journal [↗](#)



Article views: 150



View related articles [↗](#)



View Crossmark data [↗](#)

REPORT

 OPEN ACCESS

 Check for updates

Experiencing emergency services as a PhD student during the pandemic: an autoethnography of a holistic breakdown

Erika Renedo Illarregi

Department of Design, Aalto University, Espoo, Finland; Departamento de Ingeniería de Diseño y Fabricación, Universidad de Zaragoza, Zaragoza, Spain

ABSTRACT

This paper explores my first hand experience of illness during the first weeks of the pandemic, as a PhD student. Through an auto ethnographic lens, I narrate events which occurred during the month of March 2020. My memories, and their interpretation, continued to transform in the subsequent months, coinciding with the analysis of an earlier set of participants data and writing of the thesis. This paper draws upon such experiences to raise methodological and existential questions in relation to *design* research and healthcare. The short paper is structured in two parts; the first describes a few *memory fragments* to help the reader connect with that initial experience, whilst the second discusses the methodological and existential implications alongside a personal reflection, as an invitation for further dialogue within our research community.

ARTICLE HISTORY

Received 9 March 2023
Accepted 18 October 2023

KEYWORDS

Mental health; covid-19;
emergency medicine;
autoethnography; trauma

Introduction

The Covid-19 pandemic has shaken the world and our society in innumerable ways. At an individual level, it has represented a major life event for many. Being a millennial, brought up in the 90s, the covid pandemic was the first time that society as I knew it was abruptly transformed. Some of us consider this an existentially meaningful time of our lives, as we reflected on what we took for granted and engaged with *big* concerns such as life, death, even sex and relationships.

Background

A friend's supervisor used to say that either you start a PhD with an existential crisis, or you end with one. For those like me who did a PhD during the

CONTACT Erika Renedo Illarregi  erika.renedoillarregi@aalto.fi, erika@unizar.es  Department of Design, Aalto University, Espoo, Finland

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group
This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

pandemic, the very middle might have been the most existentially thrilling indeed, although it inevitably affected our PhD studies in different ways and to different extent. Whilst some people may have felt the restrictions as a methodological nuisance, having to change their research plan, others, like me, were affected in somewhat personal ways. In my case, direct experience of illness brought me unexpectedly closer to my participants and the subject. My PhD fieldwork, which consisted of co-designing with participants with mental health problems such as psychosis, had already taken place. I had completed all the workshops and the interviews face to face by February 2020. The pandemic did not have an impact in this regard, yet my own experiences during March 2020, those of being seriously unwell, did interrupt my PhD in an abrupt way. Furthermore, I do – to date – consider that those weeks transformed my orientation towards life and the world, which probably had an impact in the subsequent interpretation of data. Rather suddenly, I found myself intimately connected to the experience of being physically, mentally, *holistically* unwell.

Method

My PhD thesis combined several methodologies such as co-design, Interpretative Phenomenological Analysis (IPA), case study and mixed methods to answer a variety of questions around co-design and mental health. The results of these studies are documented (Renedo Illarregi et al. 2023; Renedo Illarregi 2022). Although inevitably intertwined, this paper is based on a separate, additional autoethnographic reflection, where I analysed my personal experiences of the unexpected events that put my PhD studies on hold.

In autoethnography, one researches the hidden experiences of only one person – the researcher – in order to provide a unique perspective on a group that can be understood by insiders and outsiders alike (Richards 2019). The paper is based on first hand experiences of poor health early during the pandemic. The memories of these events have been revisited periodically since they occurred. In the months immediately after, they were reflected upon with a therapist, as part of my recovery and alongside the analysis and writing of my thesis. During this time, I had the chance to talk to friends and family to contrast what I remembered with what they did. Progressively, the pursuit of *what really happened* gave way to revisiting the story in relation to paradigms (such as mind and body dualism) that dominate our health culture.

This paper summarizes my experience through a series of *memory fragments* that help the reader connect with the overall sentiment. Later, I draw from the story to reflect upon methodological and existential insights in relation to healthcare, concluding with a personal reflection.

Memory fragments

First windowless room

It is the beginning of March, and I am in a room without windows in some UK hospital, with my flatmate. A woman comes telling me that she must put a stick up my nose, and that none of us can leave the room under any circumstance. 'I need to go to the toilet', I say, 'well you can't, I will bring something for you to pee on'. 'It does not get more surreal' I thought 'than – following hours of inability to pass urine – having to pee all at once in a cardboard pot with the person who you are secretly in love with.

I came to hospital following the advice of a doctor on the urgent care phone number. It was early March, so Covid did not even cross my mind 'Whatever I do have they will miss it while looking for this germ'. Little did I know back then that neurological symptoms such as mine could also be triggered by the virus 'perhaps it is herpes?' 'a case of hysteria like those women in the 1920s?'

Second, third, or fourth windowless room

A Spanish nurse came in with a spaceship outfit that reminded me of Spielberg's movie E.T, told me I had Covid and began listing people I had been with. Those words were strangely reassuring. As scary as Covid might have been, things started making sense in not making sense at all, and someone was being friendly at last. After a few hours on IV, they came to say that the nurse had made a mistake and that my tests results were not out yet. Apparently, they had told the nurse to treat me as if I was Covid positive, and he understood I had Covid indeed. By then, close contacts were notified and a nursery in Berlin had been shut down as a result.

Home

Every time I was falling asleep, my breathing seemed to come to a sudden stop, and an apnoea would violently wake me up. Falling sleep, meant dying to me. I needed to be awake to keep breathing. One time I was freezing to death. Another I was asking a friend whether my eye was open 'I cannot see from my right eye'. Whether that was an isolated migraine due to panic, a transient stroke due to Covid, or an affected nerve due to a sinus infection, I will never know. What is clear is that once the doctors warned my flatmates about how my anxiety could hinder recovery, anything that I reported appeared to indicate delusion. The scary things that had made me scared, were suddenly consequences of my scare instead.

Fifth windowless room

Finally, Covid test results came back negative. We know now that the reliability of those tests was low. Back then, it felt that I was no longer a walking risk factor and was finally going to be seen. The ambulance brought my friend and I to the hospital as I asked to be seen by the mental health team, who had not been available during the weekend. On arrival one of the nurses told the paramedics that I visited several times before and that I was clearly high on drugs. I recalled that in a previous visit she had been shouting at me about putting other patients in danger. Whilst we waited, I observed the nurse diligently, until she was no longer in her uniform. I asked my friend 'did she finish her shift?' 'Yes', he said, '*thanks god*', I thought. The nurse seemed so overworked and angry at me that I feared she would 'accidentally' overdose me if she was left in charge. Shortly after, I was brought to a windowless, this time colourful, room. I was lying down, facing towards the back of the sofa, whilst two ladies behind me formulated questions about childhood trauma and history of mental health problems. They concluded that nothing could fully explain my acute onset of insomnia and wanted to do some hormonal tests. In any case, they suggested sleep medicine. I tried to refuse the pills, but the nurses said that I had been awake for so long that if I did not take anything there was high risk for psychosis. At that very moment, my research data – interview fragments from people with psychosis – formed as a thought bubble against the backdrop of the sofa. How am I going to analyse psychosis data if I become psychotic? I jumped up from the sofa shouting 'ok ok ok!', as if this sudden bounce was my only chance of moving my extremely drowsy body in any meaningful way.

The trip

'Come to Spain immediately, they are closing the border, we will help you here' my sister said over the phone. That morning the mental health team had changed my medication to long term antidepressants, and I had developed suicidal thoughts. It was my friend who noticed that this could be a side effect of the medication, upon my realization that the sudden shift from fearing dying to wanting to do so was somewhat unnatural. 'How long will it last?' I asked. '24hours', he said. '24 hours!' I cried, 'Well, no more of these'. The radio on the car said Spanish airports were already closed. I asked my flatmates what was going on, I was not following the news. My flight was to France, near the border, I could still make it. The airport was nearly empty, I noticed the military walking around, unable to grasp what was happening. I was scared to die on air. My flatmate helped me to the gate and encouraged me to take the last half sleeping pill I had left over – only because I had been stubbornly taking much lesser a dose. On landing, I saw my sister and

my dad and fell into a hug. Only that there was no *me* to be hugged. I had lost all sense of identity. I had been drowsy for over a week, but this was different. I had lost my body, I had lost my brain, now I seemed to be losing my soul. I felt that no *meness* was left over.

A room with a window

The first, or second night in Spain I started to feel numbness in my legs. My sister tried to sooth me, but we ended up in hospital. The triage doctor begun questioning me, why had I gone to hospital when *really*, I was *just* anxious. It will happen all over again, like in the UK, catch-22, no one believes me. He was – however judgemental – the first doctor who examined me. He did a reflex test on my legs, and his face changed. At that point, I was not sure if I was being admitted in the psychiatric unit for my meltdown or whether my symptoms were acknowledged as physically *real*. I was carried on wheels along the corridors, saw the mental health unit go past and arrived in Neurology. Apparently it was not safe to walk before I was examined in the morning. I had to pee in a pot, which triggered previous weeks' traumatic events. In panic, I was trying to convince my father to escape. The poor lady next must have been so annoyed at my mischief. Finally, a kind neurologist made some surprisingly enjoyable tests of moving this finger here and that leg there, and decided to run some further tests. They reassured me that a psychiatrist would visit the following day to help me cope. The second day the funny neurological ritual was repeated, and although something was still off, they noticed an improvement, so after ruling out degenerative conditions and tumours, they concluded that virus might have affected my nerves, but that the worst had already happened.

Home home

The days that followed brought back some fever, and sweaty, sleepless nights. In Spain, no one could go out except for shopping essentials. I knew how addictive the sedatives they prescribed were, so I decided to go unmedicated for a few hours a day. If I knocked myself out without pause, how would I notice if I was feeling better? So, I searched YouTube for things like alpha waves, yoga, hypnosis... anything. I remember being unable to help with a 3-year-old appropriate puzzle my niece and nephew were doing. 'Well I am not sure if resuming my thesis will ever be possible', I thought. I recalled my therapist preventing me from calling my supervisor to drop the PhD, reassuring me that as the physical symptoms improved, my cognition would too. I continued to feel extremely unwell, until one day, I surrendered. I struggled to stand up from the sofa, but my sister insisted. The feeling of

exhaustion, sickness and despair had reached the upper limit when I finally made it to the toilet, step by step. I turned around towards the living room, saw my niece, and I felt infinite love and care. I thought that is it, I may not make it until tomorrow, but it is ok, it is all good, I am home, they are there. I remember that moment, when I finally accepted the possibility of my own death, as the beginning of my physical recovery.

Discussion

Methodological questions

During the month of February 2020, I was conducting the last one-to-one interview for my PhD, having facilitated several co-design workshops in the months prior which were already being analysed. While writing up the thesis, perhaps due to the traumatic nature of what happened or because I had already obtained and analysed plenty of data, it was not deemed appropriate to delve into what this experience meant in terms of design research. However, in conducting this autoethnography I recognize that how someone is showing up emotionally in relation to a subject is a key aspect of design research that is rarely discussed in detail. Now, as a postdoctoral researcher co-designing within emergency services, the methodological relevance of my own memories has become increasingly evident for reflexivity. However, it has not been easy to make the decision to openly describe what happened and it is important to respect those who do not want to make certain disclosures. How could we support methodological transparency – especially when our experiences affect the process such as in co-design – whilst respecting our rights for privacy, and what are the implications in relation to research ethics?

Whether it is for our own privacy, or in an attempt to methodologically adapt to the context we are delving into – healthcare – our reflexivity and personal experiences have been largely left out from our publications. Akama (2018) reports on an entrenched legacy of research towards replicable and generalizable knowledge that dominates, reflected by how the conventions of design research trend towards an emphasis of reporting on technology, processes and methods as interventions into the lives of others. My account goes to question whether in somewhat *sanitizing* our findings – omitting how we personally impacted our research or how we were impacted by it – we are missing important aspects of what *our way of doing things* has to offer within healthcare.

Existential questions

In my fragments, I made some reference to the *real* cause, or what *really* happened to me. To this date, such *real* cause has remained obscure, and

with time I begun to recognize that what happens to someone's health is much more complex. Poor health is wicked, just as design (Buchanan 1992). The human body is composed by many interrelated processes, and when they start failing in new ways, even the most experienced physicians may struggle to make sense of it. Months later, doctors told me it was most likely Covid, but could have also been a complication of my chronic sinusitis, that affected my nervous system. I am even open to the idea that a regular flu created havoc due to an immune system compromised by fear. There is no way to know now. For the first few months, my focus was to understand what could explain my experiences, but my efforts would often culminate at the 'chicken or the egg' causality dilemma. My case raised questions about complexity and uncertainty in relation to healthcare, and how the care of any given individual case can fall through the cracks of a system if it depends heavily on protocols, specialism, and policy. Even before the hospitals became overwhelmed, emergency services were under-resourced. I experienced blaming, shaming and judgemental behaviour, and although I understand the exceptional circumstances may account for it, I believe there is an underlying thesis to be drawn. I fell right through the *physical* and *mental* divide that dominates healthcare. By following mind body dichotomies and monocausal paradigms, we may fail to recognize the complexity of human health, giving way to poor interpretations when we try to understand and communicate about health with one another. A PhD is a process where one navigates the edge of the unknown, and my subject specifically was mental health. Indeed, I had been exploring uncertainty in design and mental health in the past (Renedo Illarregi 2018), yet this experience made me think of the concept in relation to healthcare more at large, raising concerns about how mind and body dualism affects our services. Perhaps we have become so dependent on information and protocols, that we have forgotten how to communicate and care for one another in the face of the unknown.

Mehta (2011) for instance describes how Cartesian dualism in particular – mind and body being separate entities – affects the practice of medicine, overviewing how disease, health and treatment are defined through this position, and building up a critique by throwing light on its accomplishments, limitations and self-defeating consequences. In seeking to understand why this dualism is still alive, Mehta (2011) reviews various reasons, among which is unawareness of the philosophical framework within which clinicians operate or lack of realization of the power of such model.

In essence, beliefs about health and illness still end up alienating some people from the healthcare system, resulting in serious inequalities and dissatisfaction. Designers, by recognizing the multiple realities of participants through their research, could challenge such assumptions and support a more pluralist agenda within healthcare. Such attitude resonates with

Akama's (2018) proposition; 'what if' design research could embrace plural worlds and acknowledge omitted (dismissed) phenomena? What if these ideas were recognized as a welcome addition towards an ontological 'vocabulary' that could begin to establish a richer dialogue in design research.

Indeed, design research often starts by asking fundamental questions; what it means for people to be taken care of? what is most important to patients and clinicians? what is health? Such different epistemological standpoint, which repeatedly challenges our collaborations within clinical settings (Rothmann et al. 2016), could also be the reason why design research may help prevent people *falling through the cracks* of any given system. Ultimately, I believe designers have a key role to play in transforming healthcare so that it embraces complexity, navigates the unknown and thrives within the *wicked*.

Reflection

I believe that the interactions I experienced were not only psychologically challenging but affected my physical recovery, as my immune system was in continuous stress. I felt isolated and hopeless, hindering the physical recovery, and causing yet further anxiety, in a vicious circle.

It seems that even before services were negatively impacted by increased demand, Covid, due to its unknown nature, may have significantly challenged assessment protocols. When I first arrived at Accident & Emergency, I wanted to tell a doctor what my concerns were, what I felt was wrong, but the doctor never came. They did the test and told me to go home 'the results will be ready on Monday'. Although I believe the anxiety was already present, it was probably enhanced by not feeling there was a person, an entity, or an institution which I could count on, *listening*, taking *care*. Covid not only supposed an imbalance between demand versus resources, but also one around what is known vs unknown. There was so much uncertainty around how Covid manifested, that the focus of my care was placed in what was known – that I was going *mad* – over what was unknown – whether Covid or anything else could explain certain experiences. Perhaps ignoring the bizarre symptoms and focusing on my anxiety made everyone – except me – feel safer and more in control. The unintended consequence, however, was sheer terror. I felt alone, trapped, aware that something was wrong which nobody seemed to be acknowledging.

Throughout my journey I seemed to have kept aware of this imbalance, and somewhat took matters into my own hands. I always took half or less of the prescribed medication (possibly Lorazepam¹), and routinely went unmedicated a few hours to judge my own recovery. One night, I felt myself floating over my own body, with an apnoea, until a deep breath seemed to have embodied me back. I ran to my flatmate's room, and it was the only time I took the whole

dosage. I know now that if what I had was a real apnoea and not a hallucination – something I cannot tell for sure – taking that pill was not a good idea, yet I was terrified. I also discontinued the long-term medication (possibly Sertraline) due to unwanted side effects that I did not communicate back to clinicians. Although my lack of trust – and sneakily deciding on my own dosage – was probably beneficial in this case, I recognize a more transparent communication between patients and clinicians would be safer, even in the face of uncertainty. Even if it means doctors more often formulate sentences such as ‘I do not know what is happening to you’ or ‘I don’t know if that would work’. Indeed, when followed by ‘it must be scary, we are here to take care’ a complete lack of knowledge is far less scary. In facing the unknown, a physician can explain the situation, supporting shared decision making. By relying on the certainty of test results over the ambiguity of human account, interpreted against boundaries between the physical versus the mental, my case was one where healthcare failed on its most important function which does not depend on knowledge, *care*.

Note

1. I have added the *probable* name of the prescribed medication, which is based on my recollection but not confirmed since I could not access the medical files from abroad.

Acknowledgements

I am wholeheartedly thankful for all healthcare workers, family members and friends who cared for me. Whilst I write about how some words or actions may have hurt, I do it from a place of empathy and appreciation, with full awareness of the unprecedented circumstances and recognizing that we are all part of a system. I would like to thank to all health workers worldwide, for their courage and dedication. Many lost their lives saving ours.

Disclosure statement

No potential conflict of interest was reported by the authors.

Notes on contributor

Dr Erika Renedo-Illarregi is a researcher in co-design and mental health, interested in exploring how and why participants are impacted while designing. She is currently working on shared decision making within medicine.

References

- Akama, Y. 2018. “Spirited Away: Calling Forth Plural Worlds in Design Research.” 15th Participatory Design Conference: Workshop Position Paper. http://pd4more.urbaninformatics.net/wp-content/uploads/2018/07/Akama_Yoko_v2.pdf
- Buchanan, R. 1992. “Wicked Problems in Design Thinking.” *Design Issues* 8 (2): 5–21. <https://doi.org/10.2307/1511637>

- Mehta, N. 2011. "Mind-Body Dualism: A Critique from a Health Perspective." *Mens Sana Monographs* 9 (1): 202–209. <https://doi.org/10.4103/0973-1229.77436>
- Renedo Illarregi, E. 2018. "What Are the Effects of Co-Designing on Participants' Mental Health and Does Uncertainty Play a Role in This Change Process?." Proceedings of the 5th International Conference on Design4Health, Sheffield, UK.
- Renedo Illarregi, E. 2022. "Co-Design as Healing: Exploring the Experiences of Participants Facing Mental Health Problems." Degree Granting Institution Open University, Ed., The Open University.
- Renedo Illarregi, E., K. Alexiou, G. DiMalta, and T. Zamenopoulos. 2023. "Is Designing Therapeutic? A Case Study Exploring the Experience of Co-Design and Psychosis." *Psychosis* 15 (3): 277–291. <https://doi.org/10.1080/17522439.2022.2052450>
- Richards, R. 2019. "Autoethnography." In *Research Methods in Health Humanities*, edited by C. M. Klugman, E. G. Lamb, C. M. Klugman, and E. G. Lamb, 221–C13.P80. New York: Oxford University Press. <https://doi.org/10.1093/med/9780190918514.003.0014>
- Rothmann, M., D. Danbjørg, C. Jensen, and J. Clemensen. 2016. "Participatory Design in Health Care – Participation, Power and Knowledge." Proceedings of the 14th Participatory Design Conference on Short Papers, Interactive Exhibitions, Workshops, Aarhus, Denmark, 127–128. <https://doi.org/10.1145/2948076.2948106>