

The health of dying bodies

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Health is well-being and not just the absence of disease: how much of this definition is applied in our cities? Researcher Mara Pieri has been working for years on how to make access to health care in cities truly inclusive. Starting with a small revolution: considering health not an individual fact but a fragile privilege that concerns everyone

Healthy cities, pathogenic cities. Toxic cities, cities where you know you can be cured, or not. It depends on the city, it depends on who you are. It depends on how access to services is organised, it depends on whether you belong to the category that can access them. Health has been defined by the World Health Organisation constitution as «a state of **complete physical, mental and social well-being**¹», far beyond the absence of disease: a definition that directly calls into question the social and relational structures that make up our lives and make us, or not, well. Yet the **relationship between cities and health** is often measured only in terms of levels of environmental pollution and access to care services, because often these are not guaranteed either. And in few places like big cities, if you are sick, you risk being thrown out.

«**Illness is very often seen as an individual matter**, something that happens to you as a person and on which there is **no social responsibility** and therefore no collective plots to support you either» stresses sociologist Mara Pieri.

«If you are sick you immediately become a **less productive, reliable person**, an intermittent person, your body fails because it works less but you have to make an effort, you have to show that you are fighting, that you are fantastic, that you have all the resources to have a success story in spite of the illness». This narrative of performativity, Pieri points out, removes the fact that «**Health and illness affect each and every one of us**: any person can fall ill, can become disabled at any time of life. Health is really a very very unstable, fragile privilege, so if we think about it collectively we all gain».



Mara Pieri is a research associate at the Centro de Estudos Sociais of the University of Coimbra (Portugal). She holds a PhD in Human Rights in Contemporary Societies with a thesis on the experiences of LGBTQ+ people with chronic illnesses in Italy and Portugal, which won the Controtempo prize of the Codici Research and Intervention Foundation (Milan) and the honourable mention of the Virginia Quaresma Prize in Cultural Studies (Univ. of Aveiro). An expert in accessible and inclusive communication, she is a member of the research team of the REMEMBER project – Experiences of Older LGBTQ People in Democratic Portugal (1974-2020). She is currently leading the DIVERS – Diversity and inclusion in access to health (2022-2028) project on access to health services for the LGBTQIA+ population in Portugal.

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From performativity to interdependence

You are in pain, your body does not respond, your mind even less. But you are told to smile, to be strong, that if you want you can, and so if you can't, it's your fault after all. «We have moved from the ancient stigma of illness as divine punishment to **the current removal of the vulnerability of our bodies**, which becomes hallucinatory pressure on those who face an illness, a discomfort, a time of difficulty» Pieri points out.

A researcher at the Centre for Social Studies at the University of Coimbra, in Portugal, she has been working for years on inclusive communication and the right to health from an **intersectional perspective**: an approach that emerged in the context of feminist studies that crosses different identity categories to show how the same person or social group can be subjected to multiple levels of social discrimination.

A perspective that problematises **the asymmetry at the basis of the care relationship** itself: «Feminism has shown us that care is not always a horizontal issue, but rather is based on the subalternity of the subjects who are cared for with respect to the subjects who care» Pieri emphasises.

«The former are considered to be/are lacking with respect to the standard, somewhat emptied of their own self-determination, as opposed to the latter who take charge». From this verticality, Pieri believes that an idea of **interdependence** should instead be passed on and acted upon, in which the starting point is that we are all vulnerable and we are all fragile, for different reasons and at different times of life: instead of thinking of vulnerability as a cause of discrimination and marginalisation of aspects of one's identity and body, it would be a matter of recognising that we are **a network of self-determined people**, none of whom is deficient, who share their fragility as a strength of humanity itself».

Intersectionality for health services

So what can be done for a city that at least guarantees the right of access to health services? «The first step would be to realise that the services, the institutions, the current forms of organisation are **structured somewhat in watertight compartments**: the disabled on one side, LGBTQIA+ on the other, women on the other, as if these were communities in their own right» Pieri says. «The first piece would be **to fluidify the barriers between these groups and adopt an intersectional view**, to avoid putting people in too narrow boxes. Then there is a discourse **on the accessibility and safety of spaces**, in the sense of feeling welcome in healthcare facilities: sometimes even a rainbow flag in the outpatient clinics next to the posters of medicines and human anatomy is enough to overcome the barrier to access. And then **we need diversity education**, an accustoming at all ages to the fact that diversity is the hallmark of us human beings and the fact that we are constantly being pigeonholed does not do us justice: after all, **there is no better place for this diversity to find space than in a city**».

In her doctoral research project, Pieri investigated the experiences of young adults in Italy and Portugal who identify as LGBTQIA+ with chronic illnesses: «My study revealed **a total lack of preparation of healthcare personnel on LGBTQIA+ issues**: in the course of at least six years of training, a doctor of any speciality hardly ever holds meetings or lectures on what LGBTQIA+ means, what the difference between gender identity and sexual orientation is, what the different forms of identification of trans people are, on the existence of non-binary people, on the possible choice of trans people not to undergo hormonal surgery, on the possible danger for lesbian women of contracting

sexually transmitted diseases, etc.: topics that become important **to build a relationship of trust with people who contact the services** and to provide adequate answers. There are dramatic experiences of trans people being put in the gender department where they do not recognise themselves or faced with specialists who do not know how to handle taking hormones together with a heart problem». To bridge this gap, the international non-profit foundation *Treat It Queer*², also formed by LGBTQIA+ health workers, developed a series of pocket cards translated into several languages, including Italian. In November 2023, for the first time, the Council of Europe organised a series of meetings³ on LGBTQIA+ health, which will lead to the drafting of a policy document with recommendations for member countries.

The body at play

«From the history of queer movements we can learn creative forms of community-making, of activating networks of mutual support» says Pieri. «From my own journey as an LGBT feminist activist, I have learnt that it is very important that it is **we marginalised people who talk about our experience**, because it is often others who tell us». Meanwhile, Pieri continues to investigate people's access to Portuguese LGBTQIA+ health services after the enactment of the specific ministerial legislative framework. «I think it is a privilege to be able to do research on issues that you are passionate about, regardless of having a reference to your personal relationship» the sociologist points out. «Telling me creates forms of empathy and helps people feel less sceptical about participating in an academic project. After that, **academic life is not meant for bodies that fail**, there is always a nice dose of paradox in talking about chronic illness when there is your body that maybe doesn't come after you and you have to stop: it is always an opportunity to see the political, productive, intellectual potential of working on these concepts and also change the practices around me a bit. This is my commitment».

1. See [Constitution of the World Health Organization](#). ↩
2. See [A tool for health justice, right there in your pocket](#). In *Treat it Queer*. ↩
3. Qui il programma al primo: [Advancing Healthcare Access for LGBTI people in Europe](#) (15 Nov, 2023) ↩

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Josephine Condemi