Karolina Follis
Luca Follis
Nicola Burns

The disappearing patient: visibility, mobility and infectious disease

In the contentious debates surrounding the arrivals of migrants in Europe, some actors, notably right wing politicians, have claimed that migrants pose a threat to public health because they "bring infectious diseases."[1] In fact most migrants are healthy and migration does not cause a rise in rates of infectious diseases in host communities.[2] Instead, a different problem emerges, which this essay addresses. Migrants who arrive in Europe by sea are often "exposed to infection (particularly to HIV infection, to other sexually transmitted infections and to tuberculosis) due to frequent episodes of violence, torture, abuse and deplorable conditions of vulnerability they are submitted to along the migratory route".[3] Upon arrival they routinely receive screening for hepatitis B and C, tuberculosis and HIV. Those with a positive diagnosis are offered treatment at local clinics. But this model assumes that these migrant patients lead sedentary lives and that once they have been assigned to a clinic, they would report for prescribed treatment. In partnership with a collaborator based at a hospital in Sicily, we have gathered preliminary evidence, which suggests that in practice this is not the case.[4] Healthy or otherwise, migrants rarely settle in the first port of arrival. Instead they continue to move, disappearing from view of the doctors who first diagnose them. This means that in spite of a positive diagnosis, their medical treatment is interrupted or abandoned, endangering their own, and potentially also other lives. Our research suggests the need to examine how the trajectories of migrant patients affect their relationship to healthcare systems in host countries. In Italy and beyond, there is limited qualitative data capturing the responses of the healthcare system to migrant mobility. This impedes potential viable alternatives to the status quo, which, as we argue, does not ensure equitable access to health care and may conflict with the human right to health as both a normative ideal and a public policy goal.

---

[1] Editorial, "Migration and Health", *The Lancet Infectious Diseases,* 16, August 2016, 847.

[2] Ibrahim Abubakar, Robert W. Aldridge, Delan Devakumar and Miriam Orcutt, "The UCL- Lancet Commission on Migration and Health: the Health of World on the Move." The Lancet 392/10164, 2018, 2606-2654.

[3] Tullio Prestileo, Francesco Di Lorenzo, Salvatore Corrao, "Infectious Diseases among African irregular migrants in Italy. Just an individual problem?", *Clinical Social Work and Health Intervention*, 2/5, 2015, 45-57, here 46.

[4] As part of the Wellcome Trust-funded project *Doctors within Borders* (http://wp.lancs.ac.uk/doctors-within-borders/)we collaborate with Dr. Tullio Prestileo based a Ospedale Civico in Palermo, Sicily.

In spite of the existing entitlement (in Italy and elsewhere in Europe) to free treatment for infectious disease, the options for migrants with a positive diagnosis are not straightforward. Remaining in the local area with access to the clinic may address the patient's treatment needs but it rarely seems to answer the needs that propelled them on the migratory journey in the first place. First port of arrival may not provide access to employment, housing outside the reception center or any longer-term prospects for a sustainable livelihood. One physician who works on the frontline of Mediterranean migration has described this situation as "the syndrome of the Prometheus", that is the situation where, in his words, "you have the good fortune of having arrived somewhere where I am going to treat you for free, but this means that I am turning you into a prisoner."[5] Part of the myth of Prometheus was that Zeus punished him for his audacity by chaining him to a rock where an eagle would come every night and feed on his liver. His liver would grow back overnight and the torment would be repeated the following day. We interpret the physician's comment to mean that keeping the person alive but stuck in a place against their will is analogous to the case of Prometheus—the person's health can be maintained but they are effectively a prisoner of the system. With that in mind, this essay considers, firstly, whether irregular migrants who have been diagnosed with a communicable disease can be, in some circumstances, described as living, or existing, as Gabriel Gatti describes it, "without the conditions required for existence", and thus belonging to the category of "social disappeared". [6] Secondly, we explore related features of precarious (or vulnerable) existence, namely its circumscribed mobility and its position on the spectrum between visibility and invisibility.

Methodological uncertainties of social disappearance

For Gatti, the point of departure for his theoretical consideration of social disappearance is the historical experience of the *desaparecidos* in Latin America, that is political detainees imprisoned in secret detention centers. He discusses victims of enforced disappearance who are removed, against their will, from their environment and held, or killed, in an undisclosed location by agents of a state According to the International Convention for the Protection of All Persons from Enforced Disappearance (2006), the widespread or systematic practice of enforced disappearance is a crime against humanity. This form of disappearance is literal, that is the victims vanish from view and no one in their immediate environment knows where they are or what is happening to them. This is not necessarily the case with the extremely vulnerable persons and groups, the marginalized and socio-economically deprived whom Gatti proposes to capture under the term "social disappeared".[7] They are not necessarily actively targeted, although they might be. Sometimes they can be deprived of liberty (for example in immigration detention), but this is not always the case.

[5] Prestileo, in conversation with the authors, January 2018.
[6] Gabriel Gatti, "The Social Disappeared. Genealogy, Global Circulations, and (Possible) Uses of a Category for the Bad Life", *Public Culture,* 32/1, 2020, 25-43, here 26.
[7] Gatti, "The Social Disappeared", 26.

Social disappearance, in other words, is a figure of speech. It might be a potent and productive one, but if it is to be of conceptual use for specific cases and empirical situations it requires further fleshing out. Thus, a key question to ask is who, or what is the "social" in the social disappeared. Disappearance implies invisibility, and while with enforced disappearance such invisibility seems to be total, in cases of social disappearance it seems to be partial or relative. Disappearance from whose sight? The relative nature of this invisibility is well illustrated by one of Gatti's examples. He describes how "[i]n 2014, in Spain, a group of people with severe physical disabilities protested cuts in the dependency law that denied them healthcare coverage, and they did so with the logo 'We too are disappeared'"[8]. The protesters were trying to communicate a sense of social abandonment.[9] They called for recognition of their needs, and asserted their presence in public space in the face of a system that failed to protect them. Their claim to the designation of the "disappeared" underscores, presumably, a sense of being deliberately injured. Disappearance in this context means being made to vanish from publicly and socially productive life. This would indeed be the inevitable effect of the denial of healthcare to the severely disabled.

In this vein, on close inspection, the kinds of persons who according to Gatti collectively make up the category of the social disappeared could each be disappeared in a different sense, invisible to the eyes of different actors and for diverse reasons. The social disappearance of "futureless adolescents" is qualitatively different than that of "pensioners" or "battered women".[10] The "bad lives" of "all the pariahs" are not all bad in the same way.[11]

For example, are all irregular migrants social disappeared? They are often unseen by the state, in James Scott's sense of being unrecorded and invisible to authorities.[12] This means that their presence, whereabouts, fiscal status and social care needs are not officially registered and thus not legible to government bureaucrats. As such, those needs and circumstances that irregular migrants experience are not acknowledged and not acted upon. This in turn produces conditions of abject existence, deprivation and powerlessness. On the other hand however the same ostensibly disappeared irregular migrants might be radically visible in other ways, having struggled for and achieved a visibility that becomes a resource for survival.[13] They might be present, even if unwanted, in public spaces of European cities. They might be visible (usually in a distorted way) in their media portrayals, on the radar and the register of NGOs, charities and churches. Developing methodologies to uncover such variable dimensions of appearance/disappearance

[8] Gatti, "The Social Disappeared", 35.
[9] Joao Biehl *Vita: Life in a Zone of Social Abandonment*. Berkeley: University of California Press, 2005.
[10] Gatti, "The Social Disappeared", 35.
[11] Gatti, "The Social Disappeared", 27.
[12] James C Scott. *Seeing Like a State: How Certain Schemes to Improve the Human Condition Have Failed*. New Haven, Conn.: Yale University Press, 1998.
[13] Martina Tazzioli, "Eurosur, Humanitarian Visibility, and (Nearly) Real-time Mapping in the Mediterranean", *ACME: An International Journal for Critical Geographies* 15/3, 2016, 561-79.

and visibility/invisibly seems important to any empirical study of how "ordinary social catastrophes"[14] produce the social disappeared.

Our inquiry into the situation of irregular migrants who have been diagnosed with communicable disease highlights the complex tensions between illness, mobility, visibility and regimes of control. Effective treatment of disease requires what we might call a covenant of trust between the patient and the doctor. The doctor offers treatment. The patient submits to or implements the doctor's orders and is thus either restored to health, or his or her condition improves, or becomes manageable. For patients who are irregular migrants the forging of this covenant is obstructed by several factors. Firstly, they are unsettled in time and place. Secondly, more often than not, they do not share a common language or a reservoir of common knowledge with the doctor, requiring cultural and linguistic mediation of third persons. Thirdly, they have grounds to fear the authorities and hence be suspicious of any procedures of registration and documentation. With these factors at play, migrant patients might be willing to forgo treatment.

Finding out how and why these decisions are made remains to be revealed through research, but based on preliminary evidence we hypothesize that the disappearance of the patient is a common outcome.[15] We observe however that both patienthood and the condition of being a migrant are only aspects of a person's existence, not its essence. An individual might therefore disappear as a patient, that is vanish from the purview of the healthcare system, but still exercise their agency and autonomy as a mobile person, that is someone who has undertaken a migratory project and is pursuing it wherever it might lead. Hence, as discussed above, (social) disappearance is not an absolute condition, but a relative one, situated, so to speak, in the eye of the beholder.

Disappearance, mobility and visibility

As noted above, precarious lives are characterized by varying degrees of mobility and visibility. Those could be thought of as the parameters that help concretize social disappearance, that is help specify which social worlds do the disappearing subjects vanish from, and to what extent. Critics of the mobilities paradigm have observed that "mobility is a resource to which not everyone has an equal relationship".[16] The same could be said of visibility. Movement can take place in ways that enhance or diminish a subject's social presence. Subjects can deploy strategies and tactics that make them more or less visible. In a stark power asymmetry, state authorities can enhance their own vision to see people where they would otherwise remain unseen, or to arrest illicit mobilities.[17]

[14] Gatti, "The Social Disappeared", 37.
[15] As of the summer of 2020, further research on this project is on hold due to Covid-19.
[16] Beverly Skeggs, *Class, Self, Culture,* London: Routledge, 2004.
[17] Karolina Follis, "Vision and Transterritory: The Borders of Europe", *Science, Technology, & Human Values*, 42/6, 2017, 983-1002.

For the migrants diagnosed with communicable disease, movement is a necessity to be pursued in spite of obstacles, disincentives and punitive sanctions. As such it competes with the possibility of receiving medical treatment, which requires at least temporary emplacement, that is an abandonment of movement. Medical treatment addresses only one aspect of these migrants' lives, namely health narrowly understood as the absence of disease. Mobility offers a chance, however faint and distant, for a more complete fulfillment of needs, that is the possibility of reaching a destination conducive to living, as opposed to mere existence. People who migrate, in other words, seek something other than Prometheus's prison. In pursuit of this movement however, they abandon their status as patients, sever the relationship with the healthcare workers who are in a position to offer them treatment for communicable disease, and disappear from view. Referral, follow up and prescription renewal, all standard elements of medical care, become impossible. Data initially entered into the system about the patient remains in the system, but it may never be reconnected to the data source. In this case, mobility disrupts visibility, leading to a doubly precarious existence, as (a) an irregular migrant and (b) a carrier of an untreated communicable disease. Is this, then, a case of social disappearance?

At this stage, this question remains impossible to answer, for two reasons. Firstly, empirical data to account for the subjects' own perception of their situation remains scarce. How do they experience their relative social absence/presence? Do they feel invisible, or conversely, too visible and therefore vulnerable? After all, as Foucault noted, "visibility is a trap".[18] Secondly, from the other side, which external factors account for the migrants' possible (social) disappearance? The situation of migrant patients is, for instance, very different than the one of disabled protesters in Spain mentioned in Gatti's article and touched upon above. Rather than having healthcare withdrawn, it is offered to them. Illness is thus a means by which they can gain a measure of recognition and secure access to humane treatment, albeit not (at least not on its own) to legal residency.[19] And yet disappear they do, into the largely unmapped but growing domain of Europe's irregular population, which comes in and out of view, depending on who is looking and how.

[18] Michael Foucault, *Discipline and Punish: The Birth of the Prison*. New York: Pantheon, here 200.

[19] Miriam Ticktin, "Where ethics and politics meet", *American Ethnologist*, 33/1, 2006, 33–49.