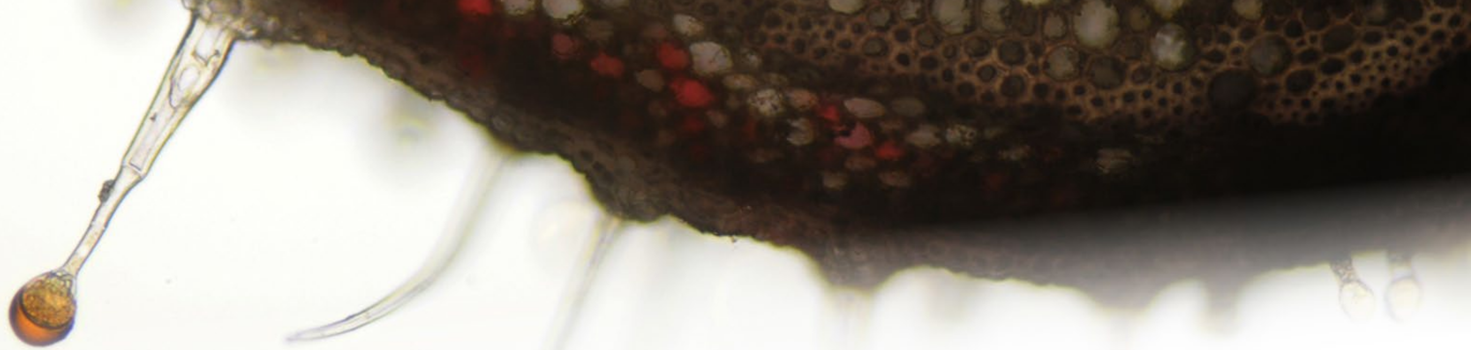

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HISTORY OF MEDICINE: PEER-REVIEWED ARTICLE

Asylums and Harm Embodiment

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Abstract
This article examines iatrogenic harms incurred by closed-ward psychiatric hospitals. In particular, this article considers roles of narrative in one patient's experience of life-encompassing iatrogenic harm from being institutionalized from infancy to age 60 and also emphasizes Italy's comparative success, relative to the United States, in recovering from decades of deinstitutionalization to establish community-based mental health care.

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Manicomio

Ethnographic and historical research can inform understanding of profound iatrogenic harm to individuals who grew up in a *manicomio* (a closed-ward psychiatric hospital) in 20th-century Italy. These persons' social identities were severely restricted and emerged only and entirely within an institutional context, resulting in long-term harms in the form of developmental, physical, and behavioral disabilities. Institutional enculturation and development of microsocial identities proved major stumbling blocks for social reintegration of institutionalized individuals during the deinstitutionalization movement of the 1960s and 1970s. These individuals embody institutional legacies beyond their spaces and structures, and their stories must be shared to avoid risk of renewed social ignorance or repetition of past abuses. After briefly discussing the history of institutional psychiatry, this article describes the case of one individual institutionalized in a closed adult psychiatric ward from infancy to about age 60.

From Moral Treatment to Deinstitutionalization

Moral treatment. In late 18th-century England, William Tuke, a Quaker, created a place for "moral treatment" of persons thought to be "mad," who, rather than being restricted in chains, spent their time working and praying in a quiet country environment. This treatment's purpose was to teach internal restraint and produce it in those who were incarcerated.[1] This curative intention was expressed not only in locating institutions in a quiet, country environment but also in architectural building design.[2] A century later, such buildings, which came be to known as asylums, were replicated as medical spaces. By the 1960s, however, attitudes toward psychiatric institutions had changed, and

asylums were now discussed as mechanisms of social control. Foucault, Goffman, and members of antipsychiatry movements in Europe and the United States described a very different version of an "asylum."[3,4,5]

Community mental health. In Italy, the democratic psychiatry movement emerged in the late 1960s and understood the *manicomio* as a place of violence and suffering in which ill persons were segregated because they were viewed as socially disruptive.[6] Italy later became known for its radical mental health reform and for Law 180, passed in 1978, which started the process of deinstitutionalization by closing all public psychiatric hospitals in the country. The transition from asylums to community mental health care centers was a slow process, finally achieved nationally in 1998.[7]

Iatrogenesis

Ivan Illich first published *Medical Nemesis: The Expropriation of Health* in 1974 as an indictment of medicine as a whole.[8,9] Iatrogenesis referred to "the disease of medical progress."[8] Physicians created illness rather than curing it, doing more harm than good. Illich also identified social and cultural forms of iatrogenesis that referred to the medicalization of Western society generally. He suggested that medicalized death, for example, removed cultural meanings from pain, "corrupt[ing] the essence of what it is to be human."[9]

From the Italian perspective, these multiple concepts of medical harm were intertwined with Italian deinstitutionalization.[6] Franco Basaglia, one of the main figures of Italian psychiatric reform during the 1960s and 1970s, condemned many social institutions, from prisons to schools to asylums: "The main characteristic of these institutions is the clear division between those with power and those without it.... Violence and exclusion underlie social relations in our society."[6] For Basaglia and his colleagues in the democratic psychiatry movement, iatrogenesis was seen as operating at the macro level, whereas today, the concept is typically used to identify surgical complications and nosocomial infections.[6,10,11] Yet the lived conditions of the aftermath of deinstitutionalization, as detailed in the following sections, remain relevant as examples of how total iatrogenesis emerges from "total institutions."[4]

The *Manicomio* Today

For many years after legal deinstitutionalization, the large provincial *manicomio* building in Bergamo, an area of northern Italy, was still used for residential community mental health care.[12] At that point, doors were no longer locked, but the building remained the same. Later, multiple local community mental health centers with residential areas were constructed throughout the province. The research center opened its main building in 1998, and additional facilities and programs were added, including a small off-site farm and horse stable.

The main building housed up to 18 adult residential patients, about two-thirds of whom had spent significant time in the *manicomio* before deinstitutionalization. The majority of center residents were male and over 50 years old. Although the goal of reform was to place everyone in communities with their families, in reality, many of the families could not be found. Other families did not want to house their deinstitutionalized relatives or did not have the resources and skills to do so. Although family members would periodically visit or attend parties and events, most residents had little or no apparent contact with family, and some had no lifetime memory of their families. The facility also housed a day program for a variable number of individuals; they typically lived with their

families or independently and commuted to the center. The day participants were more diverse in terms of gender and age, with few having resided long-term at the old *manicomio*. Center activities were mainly held for residential and day participants as a combined group.

Individuals placed in adult mental hospitals from childhood or even from infancy, who remained in the *manicomio* for up to 60 years, experienced profound difficulty reintegrating into community settings. This phenomenon was not rare; Paolino's case is described in what follows.

Paolino's Case

Paolino's case is based on my observations and interviews with center staff.[12] Paolino is a man of small, slight stature, and, at the time of my fieldwork period, he was probably in his 60s. His pseudonym is intentionally recorded here in diminutive form (the suffix "ino" added to "Paolo"), because this is how his name was used. He perpetually wore sweatpants and t-shirts, often calling them his *pigiami* (pajamas). He rarely spoke, and I learned that during the entire time he lived in the *manicomio,* he hadn't spoken at all. The few words and phrases he would use had all emerged since he had started coming to the community mental health center, and the staff spoke proudly about this improvement. His common phrases included some general greetings, such as *ciao* and references to things or activities that he enjoyed: *caffé*, *mangiamo*? (Are we going to eat?), and, in particular, *a cavallo* (horseback riding). Paolino was passionate about riding the horse, and I was at first surprised at how skilled he was at this activity. Riding was the first time I had seen him enthusiastically engage in an activity, which differed from his typically hesitant engagement with the tasks of everyday center life. Horses were one of the few things Paolino spoke about often. He used *a cavallo*! (on the horse!) as a general interjection. In the morning, he would use it as an actual question: *a cavallo*? to ask whether the group would be going to the farm. On other occasions, *a cavallo*! would express disappointment or disgruntlement with a situation, as an interjection seemingly unrelated to anything, or as an almost whispered musing.

Paolino was always ready to ride, asking about the horse multiple times per day. On the days he went to the farm, he would begin almost immediately asking if he could put on the saddle. Vincenzo, a center employee who directed the work and horse therapy sessions, would reply that he could ride the horse after the farm work was done. Paolino would typically help out by wheeling the wheelbarrow to dump the horse manure, sweeping, and brushing the horse. He needed constant supervision in each of these tasks, and he would ask repeatedly if he could put on the saddle yet. When he brushed the horse, unless his hand was guided by another individual, he would whack the brush against the horse, causing it some distress; this was not intentional cruelty, but rather due to difficulties in performing small-scale physical tasks. When the work was completed, the group would saddle up the horse, and center participants would take turns riding, which was typically done in an enclosed space, with the horse being led by Vincenzo or another participant. Paolino always had a turn.

Paolino also required supervision in many life domains beyond riding and grooming the horse. He had to be dressed by others; he occasionally wet his pants; he did not smoke, but he was a very enthusiastic drinker of espresso, which the staff had to dilute with cold water so that he would not drink it too quickly and burn his mouth; and he would wander into the traffic on the road if not watched. Other participants would tease or make fun of him because, in the hierarchy of patients, he was among the most

disadvantaged of the disadvantaged. Yet, rather than being an example of the helplessness of mental illness, Paolino must be considered a product of the *manicomio* itself. His life, lived in this way, is a direct result of past mental health policy decisions and their real historical manifestations, the full extent of which I came to learn in an unexpected manner.

On an August morning, while walking to cut grass for the rabbits, Vincenzo told Paolino to walk away from the road because of the cars. "*Sì, papá*" (yes, father), Paolino replied. This was a startling statement; Vincenzo is a man 15 or 20 years younger than Paolino. Furthermore, nobody had ever heard Paolino refer to Vincenzo in this manner before. At this point, I was walking beside a staff member, and I asked if maybe he used to do farm work with his father as a boy.

"No, he was probably abandoned as a baby," she said.

I asked where he was from, and she replied that "nobody knows" but that the staff believes he was abandoned—perhaps delivered directly to the manicomio as an infant—and after he had spent many years in the *manicomio*, nobody knew where he was born or anything else about his past. I asked how it might have happened that an infant would be abandoned at the adult *manicomio*, and she responded that nobody knew that either and that there was very little information to be found about those days. It was likely that Paolino chose *papá* as a term of endearment or respect for Vincenzo, the man in charge of the beloved horses.

Paolino is an example of an individual who never learned to live within general society or to take care of himself. According to Vincenzo, Paolino's lack of independence is a "shame," and he said perhaps little Paolo could have even learned to read under different circumstances. Instead, saying a few words is a significant improvement and achieved with difficulty. What happened to Paolino during his life? Nobody can say. His life history is expressed only in terms of questions and silence.

Microsocial Identity Formation as Iatrogenic Harm

Based on Paolino's story, it is clear that the ideological contention that all deinstitutionalized individuals can reintegrate and live within general society does not apply universally; in Italy, quick social reintegration for all was untenable. Individuals who had lived in hospitals for 20, 40, or 60 years were eventually moved to community residential facilities, but most retained their institutionally created "microsocial" identities. No attempt was made to move Paolino—who at the time of hospital closure had no identifiable family, no recorded history, no speech, and profound difficulties with everyday tasks—to community living. Instead, he stayed in the *manicomio* building until he became a resident of the new community mental health center.

As Vincenzo mentioned, institutionalization deprived little Paolo of the chance to learn. I further argue that his "psychiatric" disorder might have been mostly or entirely generated by the *manicomio* itself; it is impossible to know what types of behavioral, cognitive, physical, or speech-related difficulties he would or would not have had otherwise. Rather than having been socialized in a local community context, Paolino passed through developmental stages in a psychiatric hospital meant for adults where there was no education, no treatment designed for children, and no models of noninstitutional social interaction. His lack of speech development and difficulty with everyday tasks is consistent with other well-known studies of severely abused and

neglected children.[13] As he developed from infancy to adulthood, Paolino had no choice but to grow into a person who could survive within his impoverished world; his physical and mental development became processes of embodying the *manicomio.*

The residential portions of Italian community mental health centers were created for those who could not fully return to community and family life. They were necessary for a population with no alternatives, but they provided amelioration rather than cure. Some residents are merely waiting to die, filling the time by smoking cigarette after cigarette. Nevertheless, amelioration is much better than the alternatives, such as the chaotic world of prisons, homelessness, and institutionalization. Local community mental health centers can bring joy, meaningful work, education, opportunities for desired social interaction, and some forms of freedom. Paolino can ride horses every week with great pleasure and enthusiasm. He can drink espresso, eat freshly prepared food, and socialize with other people. This situation represents a vast improvement over his 60 years of *manicomio* life, and it may also represent the best achievable outcome for someone who spent most of a lifetime locked within an institutional world.

Lessons

Listening with discomfort. In Italy, I saw many older deinstitutionalized individuals who had been robbed of their social identities; failed health policies and extreme social isolation have consequences that can never be undone. There are many who will never have full social lives beyond the microsocial world of the mental health system. In some Italian professional circles, the term *residui manicomiali* has been used for these individuals: the "remainders," the "residue" of the institution. The implication is that the politically imagined community-based mental health system cannot become a full reality until the "remainders" get older and die.

When I was at the beginning of my fieldwork, I worried about the ethical implications of writing about someone else's suffering. Was it wrong to coopt another's suffering for an academic work? I soon came to realize that those concerns missed the point completely. The true harm resides in the unwillingness of society to listen to these stories at all. The problem here is not the exploitation of suffering; rather, it is widespread societal avoidance, concealment, or disavowal of the reality of this type of suffering. While doing my research, everyone in the center knew why I was there, and I was frequently sought out by participants wanting to tell me stories from their lives. Many expressed disappointment that I was required (by the institutional review board) to give them pseudonyms rather than using their actual names. I began to wonder who was really being protected by disguising these stories under so many layers of anonymity. Was it entirely for the benefit of the study participants, who would never be identifiable in foreign academic literature, but who had also been named and photographed for the local paper on multiple occasions? Or could the system have actually been designed in part to protect the academic reader from discomfort?

This is not to say that narratives of psychiatric institutions can only produce discomfort. The possibility of recovery is a hopeful aspect that is also essential, since there is clear evidence that it happens with frequency.[14,15] Misguided ideas suggesting that schizophrenia is permanent and incurable, together with stigma, have consigned many people permanently to the "back wards." Yet, in Vermont, 2 decades after the deinstitutionalization of patients with schizophrenia who were labeled "hopeless cases," one half to two-thirds of them had improved considerably or recovered.[16]

Nevertheless, cautions are necessary not only against misplaced pessimism, but also against excessive optimism. An increasingly common type of hyper-positivity shifts the responsibility for recovery entirely onto the individual without considering social determinants or the impacts of policy. It may be comforting for academics, clinicians, and policymakers to think every back ward harm can be fixed, but this hyper-positivity can result in refusing to listen to those stories that tell otherwise. The overall problem is not only the erasure of stories of suffering, but also the erasure of happy days, boring days, and past memories. It is an erasure of entire lives.

What the United States can learn from Italy. The current situation in the United States, with prisons as de facto psychiatric institutions and persistent problems with homelessness, reflects a failure to create a coherent or adequately funded system of community mental health treatment. Although there are people in the United States who claim that deinstitutionalization has failed,[17] the problems are more a downstream consequence of the national failure to establish or provide resources for a system of community care. The result is the "institutional circuit," whereby people cycle between institutions, homelessness, and prison.[18] At the same time, others who are actively seeking mental health care may lack access.[19,20] This lack of access is often due to the complicated mix of private and public health insurance in the United States, a country that routinely ranks near or at the bottom of health outcomes and health care access rankings among high-income countries.[21,22]

Unlike the United States, Italy did create a comprehensive national system of post-deinstitutionalization community mental health care and established laws and dedicated resources to sustain and support it. The Italian mental health system is an integrated part of an overall national health care system, and Italy ranks higher than the Organisation for Economic Co-operation and Development average for life expectancy, avoidable mortality, and population health coverage[23]; the United States ranks below average on all of these measures.[24] In a study of European countries, community-based mental health care was found to be associated with better quality of life for those with chronic problems than longer term facilities.[25] Italian researchers reported that 35 years after deinstitutionalization, the community mental health system was well established and that the continuity of care and coordination with other health and social services was high.[26] Moreover, Italy's suicide rate was less than half that of the United States in 2019 to 2020.[27]

Sisti and colleagues have argued that the United States should return to the asylum model of psychiatric care.[17] They point out that these long-term, inpatient psychiatric institutions were originally created with benevolent intent. This is a relevant point, but it also serves as an instructive foil to what came afterwards. Despite good intentions, as institutions became stigmatized and hidden from public view, they became overcrowded, and neglect and abuses increased. By the time these abuses were exposed, they had become systemic and widespread. There is no reason to believe that a new asylum, regardless of how similarly benevolent the current intentions, would evolve any differently. History shows us how rapidly the asylum becomes an oubliette, and the very existence of back wards can create the surplus of "hopeless cases" that then serve as the rhetorical justification for the asylum itself. Although we cannot fix history's ills, we can try to avoid repeating them.

References

1. Borthwick A, Holman C, Kennard D, McFetridge M, Messruther K, Wilkes J. The relevance of moral treatment to contemporary mental health care. *J Ment Health*. 2001;10(4):427-439.
2. Bartlett AE. Spatial order and psychiatric disorder. In: Pearson MP, Richards C, eds. *Architecture and Order: Approaches to Social Space*. Routledge; 1997:160-175.
3. Foucault M. *Psychiatric Power: Lectures at the College de France, 1973-1974*. Burchell G, trans. Palgrave Macmillan; 2008.
4. Goffman E. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Anchor Books/Doubleday; 1990.
5. Shorter E. *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac*. John Wiley & Sons; 1997.
6. Basaglia F. Institutions of violence. In: Scheper-Hughes N, Lovell A, eds. *Psychiatry Inside Out: Selected Writings of Franco Basaglia*. Columbia University Press; 1987:chap 1.
7. De Girolamo G, Cozza M. The Italian psychiatric reform: a 20-year perspective. *Int J Law Psychiatry*. 2000;23(3-4):197-214.
8. Illich I. *Medical Nemesis: The Expropriation of Health*. Calder & Boyars; 1975.
9. O'Mahony S. *Medical Nemesis* 40 years on: the enduring legacy of Ivan Illich. *J R Coll Physicians Edinb*. 2016;46(2):134-139.
10. Martínez-Velilla N, Herrero AC, Cadore EL, Sáez de Asteasu ML, Izquierdo M. Iatrogenic nosocomial disability diagnosis and prevention. *J Am Med Dir Assoc*. 2016;17(8):762-764.
11. Gawande A. *Complications: A Surgeon's Notes on an Imperfect Science*. Profile Books; 2010.
12. Bergstresser SM. *Therapies of the Mundane: Community Mental Health Care and Everyday Life in an Italian Town*. Dissertation. Brown University; 2004.
13. Curtiss S. *Genie: A Psycholinguistic Study of a Modern-Day Wild Child*. Academic Press; 2014.
14. Sacks O. The lost virtues of the asylum. *New York Rev Books*. 2009;56(14):50-52.
15. Warner R. Recovery from schizophrenia and the recovery model. *Curr Opin Psychiatry*. 2009;22(4):374-380.
16. Harding CM, Brooks GW, Ashikaga T, Strauss JS, Breier A. The Vermont longitudinal study of persons with severe mental illness, II: long-term outcome of subjects who retrospectively met *DSM-III* criteria for schizophrenia. *Am J Psychiatry*. 1987;144(6):727-735.
17. Sisti DA, Segal AG, Emanuel EJ. Improving long-term psychiatric care: bring back the asylum. *JAMA*. 2015;313(3):243-244.
18. Hopper K, Jost J, Hay T, Welber S, Haugland G. Homelessness, severe mental illness, and the institutional circuit. *Psychiatr Serv*. 1997;48(5):659-665.
19. Coombs NC, Meriwether WE, Caringi J, Newcomer SR. Barriers to healthcare access among US adults with mental health challenges: a population-based study. *SSM Popul Health*. 2021;15:100847.
20. Ojeda VD, Bergstresser SM. Gender, race-ethnicity, and psychosocial barriers to mental health care: an examination of perceptions and attitudes among adults reporting unmet need. *J Health Soc Behav*. 2008;49(3):317-334.
21. Woolf SH, Aron LY. The US health disadvantage relative to other high-income countries: findings from a National Research Council/Institute of Medicine report. *JAMA*. 2013;309(8):771-772.

22. Schneider EC, Shah A, Doty MM, Tikkanen R, Fields K, Williams RD II. Mirror, mirror 2021: reflecting poorly: health care in the US compared to other high-income countries. Commonwealth Fund; 2021. Accessed June 13, 2022. https://www.commonwealthfund.org/sites/default/files/2021-08/Schneider_Mirror_Mirror_2021.pdf
23. Health at a glance 2021: OECD indicators: highlights for Italy. Organisation for Economic Co-operation and Development. Accessed April 29, 2022. https://www.oecd.org/italy/health-at-a-glance-Italy-EN.pdf
24. Health at a glance 2021: OECD indicators: highlights for the United States. Organisation for Economic Co-operation and Development. Accessed April 29, 2022. https://www.oecd.org/unitedstates/health-at-a-glance-US-EN.pdf
25. Taylor Salisbury T, Killaspy H, King M. The relationship between deinstitutionalization and quality of care in longer-term psychiatric and social care facilities in Europe: a cross-sectional study. *Eur Psychiatry*. 2017;42:95-102.
26. Amaddeo F, Barbui C, Tansella M. State of psychiatry in Italy 35 years after psychiatric reform. A critical appraisal of national and local data. *Int Rev Psychiatry*. 2012;24(4):314-320.
27. Organisation for Economic Co-operation and Development. *A New Benchmark for Mental Health Systems: Tackling the Social and Economic Costs of Mental Ill-Health.* OECD Publishing; 2021.

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