Unit 10 - From the Asylum to Care in the Community:
From Paternalism to Autonomous Decision Making
Reading

This lecture examines the long development of ideas and practices of caring for those deemed incapable of making their own decisions, and the more recent development of social and legal apparatus to enable autonomous decision making over healthcare by those with reduced capacity. Whilst this potentially covers a broad spectrum of people, in the lecture we will focus especially on the changes in the way the mentally ill have been treated in medicine. Over the course of this lecture, we will see that there has been a long-term change in the treatment of such patients from a paternalistic approach that dictated what consisted of appropriate treatment to patients, to an approach that attempts wherever possible to enable patients to make informed decisions regarding their welfare and healthcare. However, in doing so, this has potentially left patients neglected.

The lecture is split into four sections. In the first section, we will examine the drive towards institutionalising the mentally ill in asylums as the ‘therapeutic optimism’ in psychiatry in the nineteenth century dictated that patients be separated from society for treatment. The second section focuses on a large section of such patients—women deemed to be suffering from the condition known as hysteria. In the third section, we examine attitudinal shift from paternalistic views of mental health treatment towards a patient-centred approach that saw mass deinstitutionalisation of mentally ill patients, replaced by ‘care in the community’ approaches, which have been inconsistently implemented. The fourth section examines the development of the social and legal apparatus to enable those with reduced capacity to make autonomous decisions over their own care in the form of advance directives, especially focusing on Do Not Attempt Resuscitation (DNAR) and Legal Power of Attorney (LPA) orders.

It is important to note that in this lecture several terms will appear, such as ‘insane’ and ‘asylum’, which are no longer deemed appropriate to use in medical practice. They are used—sparingly—in this lecture to remain faithful to the historical content of the lecture. In doing so, not only will the development of ideas and practices regarding mental illness be highlighted, but the changes in the way that we discuss those ideas and practices. Modern practice in treating the mentally ill, and the terms used to discuss it, is focused on sensitivity, understanding, and respecting the dignity of patients. It was not always so, and understanding that development is important in providing perspective on why certain terms are no longer used, and deemed unacceptable in modern practice.

1. Into the Asylum: Paternalistic approaches to Treating the Mentally Ill

As long as there had been theories of how the body worked in health and disease, so there were theories regarding the health and disease of the mind. Naturally, these were varied depending on time and place, with the societal view of what constituted mental illness and its relative value or threat to society—as well as ideas around treatment or otherwise—varying as a result.

In the west, philosophers and medical theorists put forward new ideas about how the mind was formed and worked throughout the Enlightenment—the period from the seventeenth to nineteenth century where intellectuals promoted reason and the evidence of the senses as the primary source of knowledge. René Descartes (1596–1650), who engaged in dissection work, put forward what is now known as the 'mind/body problem', which posited that the mind and body were separate entities, the problem being how they were connected. Thomas Willis (1621–1675) produced one of the first detailed anatomical works on the brain, and was especially interested in how the soul acted on the body. Later, the philosopher John Locke (1632–1704) argued that when humans were born, their mind was a tabula rasa—a blank slate—upon which impressions were, and could be, made through sense experience as well as learning.

Such medical and philosophical ideas shaped medical theories of mental illness. One of the most influential medical teachers of the eighteenth century, William Cullen (1710–1790), employed a Lockean framework of the mind to explain madness. Working on the basis that sense-data was transformed into 'ideas' in the mind; he argued that there were two kinds of madness. Some types of madness were anatomically located in the nerves, but others were due to the mind's unusual or illogical associations of 'ideas'. Thus, madness was often a psychological condition requiring treatment of the psyche. Just as for regular diseases, Cullen advocated that case histories of insane patients should be made to improve diagnosis and treatment.

In the nineteenth century, psychiatry began to form as a professional discipline, with the asylum becoming the centre for treatment of the mentally ill. Asylums had long been a feature of treating madness, but its methods of treatment within their walls were rapidly changing. Previously, the emphasis had been on restraint, with notorious asylums such as Bedlam often chaining patients to the wall in order to keep them from harming themselves and others. As William Hogarth's famous set of prints, A Rake's Progress, showed, members of the public could pay to see the mad as a pastime. But toward the end of the century, a new 'moral treatment' for the mad began to be employed. The York Retreat set up in 1796 by the Quaker businessman William Tuke (1732–1822) was one of the first asylums purpose-built for this practice, and focused on treating the inmates humanely. They avoided restraint wherever possible, encouraged what were viewed as 'healthy habits' in patients, but kept patients under close supervision at all times. The historian Edward Shorter noted that such attempts at better treating the mentally ill were not completely new, but had been fostered by Enlightenment ideals. The shift in restraining dangerous individuals to surveillance at the asylum was mirrored by a subsequent shift towards attempting to properly treat and cure individuals, and there was a therapeutic optimism in psychiatry that encouraged experimentation with different ways of curing the mentally ill, such as mesmerism and phrenology.

Asylums were built across Britain in the early nineteenth century, creating enormous capacity to house the mentally ill away from society. In the course of the nineteenth century, the total population of asylums rose from around 5,000 patients in 1826 (in a mix of private and public asylums) to over 74,000 in public asylums alone by the end of the century. Academics such as Michel Foucault have argued that this was largely an extension of state control over individuals deemed deviant. Many of those entering into asylums were poor 'lunatics' who needed to be cared for somewhere, with families often central to the admission of their relations into the care of asylums, especially in hard times. Unscrupulous husbands were also known to dump unwanted wives in asylums in what was known as a 'madhouse divorce'. Once a patient was admitted, it was uncommon for them to leave—which was one of the main reasons behind the huge expansion in the total number of patients in asylum care. At the same time, the focus of asylum care was surveillance. Some asylums were designed along the principles of 'panopticon' design promoted by Jeremy Bentham (1747–1832). Derived from the Greek term for 'all seeing' (panoptes), the idea was to design buildings (such as prisons, hospitals, and asylums) in such a way that any one inmate could be observed by a guard, nurse, or doctor at any time. At their worst then, asylums were thus instruments of control as much as they were of possible cure.

2. Hysteria: A Means of Control?

How did psychiatry and the asylum exert control over its population and wider society? We will consider the case of hysteria, a disease that was first described (in the western tradition) in ancient Greece, but gained a particular prominence in psychiatric diagnosis in the nineteenth century, and continued as an important condition in psychology in the early twentieth century.

The term hysteria derives from the word Greek word for womb, 'hystera' (which in turn derived from the Sanskrit word for stomach or belly), and was understood as a disease effecting women. One Hippocratic text wrote that in women, 'the womb is the origin of all disease'. Galen held that sexual deprivation could cause the disorder and so for Galen, treatments for hysteria neatly revolved around martial sex for married women, and marriage for unmarried women. However, the definition gradually changed—by the nineteenth century, the understanding of its causation had entirely reversed to being caused by overstimulation of the genitals, for example. The historian Mark S. Micale identified four main shifts in the understanding of the disease: first there was a gynaecological understanding, then demonological, then neurological, then psychological.

The symptoms of hysteria were diffuse, but in the nineteenth century, the Parisian doctor Jean-Martin Charcot (1825–1893) attempted to better define the disease, as he had for a series of neurological disorders such as multiple sclerosis, aphasia, Tourette's syndrome, and locomotor ataxia. As the disease left no physical trace, he employed photography in an attempt to identify the disease's different stages, providing a seemingly objective truth to his four-stage definition: 1) epileptoid fits, 2) 'the period of contortions and grand movements', 3) 'passionate attitudes', and 4) final delirium. He believed that these stages could be brought on by hypnosis, and demonstrated this to his students during his famous lecons du mardi (Tuesday lessons), immortalised by André Brouillet's (1857–1914) painting that shows Blanche Wittman (sometimes termed the Queen of hysterics, 1859–unknown) swooning into the arms of Joseph Babinski (1857–1932) with her blouse falling over her shoulders. Such displays were transgressive and erotic, and served to define hysterical patients in a certain way—in an era where photographs took twenty minutes to take, they were posed and deliberate representations.

Furthermore, there was little by way of therapeutic progression in the treatment of hysteria as a result of this work. The main treatment remained the 'rest cure' developed by the American physician Silas Weir Mitchell (1829–1914). The rest cure usually lasted six to eight weeks, depending on individuals. It involved isolation from friends and family, enforced bed rest, and nearly constant feeding on a fatty, milk-based diet. Patients were force-fed if necessary—effectively reducing patients to the dependency of an infant. Nurses cleaned and fed them, and turned them over in bed. Doctors used massage and electrotherapy to maintain muscle tone. Patients were usually prohibited from reading or writing and sometimes even talking or sewing. Mitchell believed the point of the rest cure was physical and moral: it boosted the patient's weight and increased blood supply. It also removed the patient from a potentially toxic social atmosphere at

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home. However, some historians have argued that the implicit point was the neurologist breaking his (almost always female) patient's will, and exerting control over them. The rest cure was abhorred by Virginia Woolf (1882–1941) and described by Charlotte Perkins Gilman (1860–1935) in her short horror story, The Yellow Wallpaper.

Other therapies were attempted. Notoriously, Isaac Baker Brown (1811–1873) performed clitoridectomies on hysterical patients in the 1860s. Whilst he was expelled from the Obstetrical Society for his work, it nevertheless emphasises the close link between hysteria and supposed sexual deviancy in women. Perhaps this is why the invention of the vibrator has often been attributed to doctors' attempting to cure hysterical women, but this story is insufficiently supported by historical evidence. Vibrators were sometimes advertised as panaceas however, implying that they would cure the disease.

A radically new approach to hysteria was developed in the early twentieth century by a student of Charcot's however: psychoanalysis. Sigmund Freud (1856–1939), his mentor Josef Breurer (1842–1925) and their patient Bertha Pannenheim (who has been known to posterity as Anna O, 1859–1936) developed the 'talking cure' for hysteria after finding that by talking about symptoms' onset and tracing them back to a traumatic event, a catharsis would occur that would make the symptoms disappear. This treatment formed the foundation of a radically new approach to hysteria, which framed hysteria as a sign of education and success. Freud's reports on hysteria stressed the psychological aspect and eventually argued that the symptoms of his hysterical patients were somatic expressions of repressed psychological distress, often of a sexual nature. Though therapeutically very different, hysteria was once again linked to women's sexuality.

Freud's theories enjoyed an enormous vogue in the early twentieth century, but were undermined by their pseudoscientific nature (all opposition to the theory could be explained by the theory) and new problems emerging in psychiatry such as shell shock. Hysteria gradually reduced as a diagnosis in psychiatry, whilst concurrently women's sexuality began to be understood differently, especially from the 1960s. At the same time, the paternalistic attitudes of medicine were being challenged, leading to new ways of housing and treating the mentally ill.

3. Deinstitutionalisation and Care in the Community

In the twentieth century, asylums were criticised for a number of reasons. The asylum system was seen to have failed therapeutically. The therapeutic optimism of the nineteenth century had disappeared as statistics and experience showed a very low cure rate for patients. There had been developments in therapeutics at the asylum, but their legacy was questionable. The new therapeutic methods focused on anatomically understanding and curing the brain through surgical procedures such as lobotomies, and treatments like electric therapy. There were also concerns about the morality of locking patients away, especially due to the long-term nature of asylum care, which found cultural expression in books (and films) like One Flew Over the Cuckoo's Nest by Ken Kesey.

More generally, attitudes around mental health and illness began to change, especially after the Second World War. The rejection of eugenics and mass traumatisation of soldiers encouraged mental illness to be taken seriously, with new efforts at understanding the problem and research into mental health. Then the pharmaceutical revolution encouraged a chemical understanding of the mental illness with the attendant claim that it could be treated chemically. Drugs like Prozac could be effective, and worked alongside new treatments like Cognitive Behaviour Therapy.

One of the major results of these developments was the shift from asylum care to care in the community. Asylums were expensive. Long stay patients were common, and in 1953 half of hospitals in Britain were dedicated to mental health treatment. The political right were concerned about the cost of housing so many patients. At the same time, the political left argued against the control the asylum exerted over the individual, most notably in Foucault's Madness and Civilisation (1961), and worked to tackle the stigma associated with mental illness—they promoted the idea that mental illness might be chronic, but it was manageable and individuals with such issues could contribute to society.

In Britain, new kinds of mental health provision were introduced to encourage a 'care in the community' approach. Day hospitals became places of treatment and support without being the permanent, controlling environment asylums had sometimes been. Additionally, there was a much greater reliance on self-care and self-medication in the day-to-day routines of mentally ill patients, alongside an increase in the range of available treatments. Meanwhile, in residential hospitals policies changed. Dingleton Hospital ran an 'open door' policy, which consisted in literally leaving doors open within the hospital, as well as to outside. To better integrate patients who had stayed in hospital, new transitional homes were introduced to enable a gradual reintroduction of the patient into society in a supportive environment. From the 1940s and 50s, areas trialled care in the community approaches that aimed at reducing the number of in-patients, and found success, such as Mapperly Hospital in Nottingham reducing in-patient numbers from 1,310 in 1948 to 780 in 1960.

From the 1970s and 80s, community care began to exclude the hospital altogether. The 1981 Care in the Community Green Paper recommended shifting resources from the NHS to local councils and voluntary associations, and in 1990 was implemented in law, spelling an end to the old county asylum system, with the role of Social Services growing as a result.

But the practical result of deinstitutionalisation has largely been viewed as a failure in Britain. The idea of 'care in the community' was not matched by the reality that not enough support or care was available, and that the combination of local councils—whose budgets are complex and have been the subject of severe cuts in Britain—and voluntary organisations could not keep up with demand. Today around 100,000 people are admitted for psychiatric care per year, but their average stay is only two weeks. The sociologist Andrew Scull has argued that the reality has been of 'community neglect'—communities sometimes feared the mentally ill—with 'catastrophic' results.

4. Autonomy in Healthcare: Lasting Power of Attorney and Do Not Attempt Resuscitation Orders

Alongside changing frameworks of care for those without full capacity, legal frameworks have changed to account for the more patient-led aims of modern healthcare. In Britain, the Mental Capacity Act (2005) solidified the legal framework through which advance directives could operate. Lasting Power of Attorney (LPA) and Do Not Attempt Resuscitation orders (DNAR) are two examples of advance directives in healthcare, and require individuals to have sufficient mental capacity to make such decisions. In that regard, core principles regarding such decision making were developed to ensure that patients with less capacity were indeed having their wishes heard.

The Mental Capacity Act was developed whilst deinstitutionalisation and its initial problems occurred. In the 1995 Law Commission report on mental incapacity, the social context was described as emphasising the legal context as "one of incoherence, inconsistency and historical accident", making legal reform both necessary and urgent. The central concern of the report was effect that the shift from paternalistic models of care to community care had on making decisions for those without capacity. The report, which identified its primary concern as the elderly and the mentally ill, described the previous model as effectively paternalistic—in institutions, decisions were made on the patient's behalf. However, in the new care in the community model there was little clarity over who, what, or how decisions could be made on behalf of patients, which led to some cases of abuses of power. As a result, the purpose of the report was to provide a clear legal framework through which decisions could be made in the best interests of patients in the new deinstitutionalised setting.

Both LPA and DNAR are important examples of modern attempts to enable patient choice in healthcare: LPA gives another adult legal authority to make certain decisions for someone if they lose the capacity to do so themselves; DNAR instructs healthcare professionals not to attempt cardiopulmonary resuscitation (CPR) in cases of sudden cardiopulmonary arrest. At the core of LPAs and DNARs is the basic principle that individuals should be allowed to choose for themselves, either via advance directive or via a trusted person who will look after their interests, and are potentially available to anyone.

However, ensuring that individuals—especially those already very ill or mentally ill—are able to make fully informed choices about their future selves is very difficult. As a result, the Mental Capacity Act rests on five principles through which legal orders like LPAs and DNARs are intended to work. The principles, as summarised in the BMJ, are:

Principle 1: Capacity should always be assumed. A patient's diagnosis, behaviour, or appearance should not lead you to presume capacity is absent.

Principle 2: A person's ability to make decisions must be optimised before concluding that capacity is absent. All practicable steps must be taken, such as giving sufficient time for assessments; repeating assessments if capacity is fluctuating; and, if relevant, using interpreters, sign language, or pictures.

Principle 3: Patients are entitled to make unwise decisions. It is not the decision but the process by which it is reached that determines if capacity is absent.

Principle 4: Decisions (and actions) made for people lacking capacity must be in their best interests.

Principle 5: Such decisions must also be the least restrictive option(s) for their basic rights and freedoms.

Despite the efforts that have been made to ensure that LPAs and DNARs are ethically sound, they have come under criticism for a number of different reasons. At a practical level, these decisions and judgements about capacity are difficult to make and require interpretation, which can be especially tricky when a patients' condition deteriorates rapidly or suddenly. Family resistance to the taken decision might also put severe pressure on medical professionals to change or ignore advance decisions. Another potential issue is that families cannot make decisions such as DNAR on behalf of family members who did not organise an advance directive prior to their incapacitation. In some cases, the likely wishes of those individuals might be well-known, but this is deemed insufficient to determine patients' 'best interests'. More fundamentally, advance directives have been criticised for offering an unrealistic expectation of controlling complex processes such as dying.

5. Conclusions

This lecture has examined the long social and legal move towards personal autonomy and care in the community from paternalistic models of caring for those with less capacity. We have focused on the mentally ill in this lecture, but this change has affected other groups, such as the elderly and disabled. We have examined the major changes in the effect that this has had on how the mentally ill were treated, housed, and understood by society. But the current problems with care in the community and advance directives should give us pause to reflect on the success of these changes. It is not simply the case that the move away from paternalistic approaches in healthcare has improved the experience of patients, despite improvements certainly having occurred. It is vital that the pitfall of 'community neglect' for such patients is avoided in future healthcare to ensure that proper treatment is afforded to the most vulnerable.

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