

From sick role to practices of health and illness

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CONTEXT Health care research generally, and medical education research specifically, make increasingly sophisticated use of social science methods, but these methods are often detached from the theories that are the substantive core of the social sciences. Enhanced understanding of theory is especially valuable for gaining a broader perspective on how issues in medical education reflect the social processes that contextualise them.

METHODS This article reviews five social science theories, emphasising their relevance to medical education, beginning with the emergence of the sociology of health and illness in the 1950s, with Talcott Parsons' concept of the

'sick role'. Four turning points since Parsons are then discussed with reference to the theory developed by, respectively, Harold Garfinkel, Michel Foucault and Pierre Bourdieu, and what is called the 'narrative or dialogical turn'. In considering these, the author argues for a theory-grounded research that relates specific problems to what Max Weber called the 'fate of our times'.

CONCLUSIONS The conclusion considers how medical education research can critique the reproduction of a discourse of scarcity in health care, rather than participating in this discourse and legitimating the disciplinary techniques that it renders self-evident.

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 INTRODUCTION

Research in health care generally, and in medical education specifically, rests on social science methods, but social science theory, although frequently referenced in passing, seems to have less effect on the formulation of research problems. The case put on trial in this article is that *theory*, as multiply defined as it is, represents the capacity to connect local research projects on specific issues with a conception of what Max Weber called ‘the fate of our times’.¹

I would nominate that phrase – the fate of our times – as the best short description of what social science seeks to understand: what is particular to a given historical period, and how those particularities constitute the *fate* of those who live then. That fate may involve peace or armed conflict, prosperity or economic depression, acceptance of inequalities or revolt against them, unquestioned belief systems or systematic uncertainty. Theory does not simply editorialise on the fate of any given time. Theory presents a vision of society that is grounded in empirical observation but is more than the sum of observations alone. Theory understands observations within the framework of specific concerns about how collective life is assembled. Thus, theory both derives from observations and informs understanding of what is observed.

In the mid-20th century, sociology of health and illness began with a specific focus on medical education that produced two seminal studies: the University of Chicago study that resulted in *Boys in White*,² and the Columbia University research that produced *The Student Physician*.³ These works are now more than a half-century old. This paper introduces several of the most significant developments in social theory to occur during that half-century, not in order to prescribe how these developments might affect research and policy in medical education, but with the intention of making available a range of resources for others to apply.

 TALCOTT PARSONS: MEDICAL ROLES AND MODERNITY

Talcott Parsons’ conceptualisation of what he called the ‘sick role’ has the most significant claim to represent the root of social scientific consideration of the medical complex.⁴ In brief, Parsons argued that being sick is a *role*, which means that certain expectations come with identifying oneself as sick. These

expectations involve a balance of rights and obligations. A sick person is entitled to be relieved of normal work and family responsibilities, but is subject to a obligation to seek medical treatment and comply with doctors’ orders. The role of the doctor is to provide legitimation that the patient actually is sick and thus entitled to the ‘permissive’ aspects of the sick role, but, within that, the doctor is to be wary of patients enjoying what Parsons called the ‘secondary gains’ of illness.

When I began doctoral study in 1970, none of my fellow students agreed with Parsons, but that was his gift to us. Parsons gave my generation a well-articulated theory to oppose, and nothing inspires thinking as well as feeling the need to correct ideas that are pervasive and well defended but seem wrong. Parsons’ more positive contribution was to make it self-evident that the institutional shape of the illness–health–medicine complex can be understood only within more extensive conceptualisations of how a society works. Whatever specific topic Parsons addressed, his way of imagining that topic was integrated into his sense of the fate of his times.⁵

It is important to recognise that when Parsons formulated his typification of the sick role, he had little interest in the experience of being ill. Instead, the sick role makes the action of the doctor paramount. The doctor first legitimates the sick person’s withdrawal from normal responsibilities, and later requires the patient to give up being sick and return to those responsibilities. What is at stake for Parsons that requires positioning the doctor as the key actor?

Parsons, forming his mature ideas in the 1930s, understood the fate of his times to be the open question of whether capitalist democracy would survive. That survival was in question during the Great Depression and prior to revelations of the horrors of Stalinism, when non-capitalist state organisation seemed a viable option. Parsons wrote to defend a particular conception of modernity, which depended upon capitalist democracy, which, in turn, depended on the professions; but why does so much weight fall on professions?

The professions, culminating in medicine, represented the productive synthesis of what Parsons thought of as an orientation to self-interest and an orientation to the collectivity. The former is quintessentially capitalist, and the latter socialist. On the self-interest side, doctors collect fees and are – sometimes today and generally at the time Parsons was writing – effectively capitalist operators of small

businesses. Yet on the collectivity side, doctors put the needs of their patients first; their orientation is to the needs of the collectivity. Thus, for Parsons, the doctor as a professional represents the realistic possibility that capitalist democracy can achieve a workable balance between capitalist self-interest and socialist interest in the collectivity. If Parsons were alive today, I think he would be most disturbed to see doctors working as employees of third-party, corporate entities that, in the USA especially, are responsible to shareholders. He would also be upset by scandals involving doctors in conflicts of interest as a result of ownership in pharmaceutical and medical supply companies. Both trends clearly threaten the fragile self-collectivity balance that, for Parsons, defined the professional role, which, in turn, demonstrates the viability of democratic capitalist modernity.

Parsons' thinking was most significantly *theoretical* not in the obvious sense of being expressed in esoteric concepts arranged in hierarchies and diagrams. His work is certainly filled with conceptual jargon and complex schematics, but I understand these as superficial. Parsons' sense of theory lay in conceiving problems within concentric layers of contextual significance, while linking any specific issue to what he took to be fundamental problems, like the survival of capitalist democracy. Parsons' essential lesson is to teach social scientists never to think of the illness-health-medical complex in isolation, but always as reflecting the fate of the times, however we understand that.

My praise of Parsons' mode of thought should not be understood as agreement with his substantive assessment of medical work. My youthful good fortune was to be shown a way out of Parsonian thinking, which had been charted by a student of Parsons, Harold Garfinkel, in what he called *ethnomethodology*. Garfinkel set Parsons on his feet by grounding sociology in detailed observation of how people *accomplish* the settings in which they live, whether these are courts, classrooms or clinics.

HAROLD GARFINKEL: WORK AND INSTITUTIONAL ORDER

Garfinkel's⁶ most enduring contribution can be described as shifting the pride of place from institutions, which were paramount for Parsons because they guarantee continuity of normative expectations, to individuals who are understood as *artful* in how they play with and sometimes against what is expected of them. *Role* thus becomes a form of *performance*, and

normative expectation is reconceptualised as the *work* of rendering orderly a reality that requires constant ordering. In Garfinkel's understanding, everybody works to sustain a setting. In a clinic, some people work at being patients and others work at being nurses, doctors or admissions clerks. But whatever happens is a form of work, and all the forms of work depend on one another. Ethnomethodology, most simply described, is the study of how people do the work of sustaining commonly shared understandings and the institutions that depend on these understandings.

Work for Garfinkel is the existential task of keeping life ordered, which means making people's actions mutually recognisable and acceptably predictable; this work precedes working in the sense of performing specific tasks. *Work* in the ethnomethodological sense creates the conditions necessary for *working* in the conventional sense. Work creates order, understood as when each knows what the others are doing. I call this task of ordering *existential* because ethnomethodology, at least in its most provocative early days, imagines human life as a constant struggle against the threat of the unrecognisable. We humans fear what cannot be readily typified or put into a recognisable category. For ethnomethodologists, organised collective life always hovers much closer to breakdown than people will allow themselves to recognise. The ethnomethodologist is one willing to confront this abyss.

Garfinkel's emphasis on *work* prepared for the emphasis that has become generalised in social science today. Social scientists first and foremost study people's everyday *practices*. Ethnomethodology opened up the process of studying how medicine is actually done: how professionals, administrators, patients and even investors perform the multiple practices that constitute what we call health care. Similarly, ethnomethodology can be applied to understanding how teachers, administrators, students and patients perform the practices that constitute health professional education.

Medical education teaches practices, obviously. Students learn how to do things, including how to act in ways that sustain the order of the health care setting. Less obviously, education inculcates a sense of the self-evidence of doing things that are, at first, unnatural – such as cutting open bodies – and doing them in specified ways. Least obviously, education teaches students how to balance the sometimes conflicting results of different clinical practices. In her study of atherosclerosis, Mol's main example is the

institutional production of an agreed-upon intervention, although different findings are produced by angiography and Doppler imaging.⁷ Medical students have to learn the technical practices that produce such findings, and they also have to learn to practise medicine according to the unwritten and perhaps even unspoken conventions that decree whose findings take precedence for what clinical purposes.

MICHEL FOUCAULT: DISCIPLINARY PRACTICE

Michel Foucault was one of the most prominent philosophers of the later 20th century, influencing scholars in fields from literature to medicine and medical education. Foucault's version of philosophy emphasised the institutional and political production of knowledge; his ongoing concern was with the production of what is valued as truth. His diverse research began with the study of psychopathology and led through work on the origins of modern clinical medicine. When Foucault became truly influential with the publication of *Discipline and Punish: the Birth of the Prison*,⁸ in French in 1975 and in English in 1977, he kept practices central – discipline, surveillance and punishment are analysed as practices of dividing time and space – but he added what Garfinkel left out, which is power. Although Foucault never studied medical education specifically, he would have understood it to be continuous with the practice of clinical medicine.⁹ For Foucault, medical education would be about the production of bodies that are disciplined – health care workers – so that they will then discipline other bodies.

Of Foucault's three great insights, the first is that power operates upon bodies through the application of knowledges to those bodies. Those knowledges might pertain to economics or penology or surgery. What Foucault called *discipline* is the systematic application of formalised knowledge to *normalise* bodies, according to schemes of normalisation asserted in the relevant knowledge. In medicine, the core principle is the division of the normal from the pathological.¹⁰ This division legitimates interventions to bring pathological bodies within normal parameters.

Secondly, power is only occasionally repressive. Power is equally productive, producing benefits, culminating in the production of life itself. Foucault did not question the practical benefits of medicine or other institutions.¹¹ When he became ill at what proved to be the end of his life, he went to a hospital. 'My point is not that everything is bad,' he said in an interview,

'but that everything is dangerous, which is not exactly the same as bad¹².' The problem is that the benefits brought by disciplinary power can blind us to its dangers.

Thirdly, power is not something that is 'out there' or external. Instead, power insinuates itself in individuals' self-judgements, their goals and aspirations, and their impositions on themselves, including forms of self-discipline that Foucault sometimes called 'techniques of the self' and sometimes called 'care of the self'.¹³ All three of these insights depend on studying power as relationships. If *roles* are what count for Parsons and *performances* for Garfinkel, Foucault's focus is always on *relations of power*.

What, then, was Foucault's take on the fate of our times? As I now understand Foucault – and his texts encourage readers to change their minds – people do not require critical theory in order to recognise and respond to most of life's injustices. These are generally self-evident; an example is the suffering caused by lack of medical services. Social science may be most necessary to sort out lives of comparative privilege – the lives of those who are able to be treated – because benefits and dangers are densely intertwined. In ethnomethodological terms, we need to examine our actual practices in terms of how we employ different knowledges to discipline ourselves in diverse ways. Foucault followed Garfinkel in presuming that people are already expert in living their own lives. What our times condition people to lack is a reflective sense of how engagements in their own practices weave the nets that impair their freedom. People are generally clear about the immediate intended effects of their actions. They are less clear about how an aggregation of actions brings about a particular kind of world, especially in terms of the primacy of certain sources of value and the complementary neglect of others. In health care today, the generally unquestioned primacy of *efficiency* is an example.¹⁴ We ourselves weave the nets that hold us.

Foucault held on to an ideal of freedom,¹³ although what he meant is complicated. He criticised popularised forms of *liberation* as self-imposition of external knowledges. Freedom cannot be bought second-hand from a self-help programme, or a chat group or a well-intentioned clinician. Freedom may be achieved through practices of care of the self, but which of these practices lead to freedom and which are internalised self-disciplines remains subtle to distinguish. It may not be that Foucault's death stopped him from articulating a clear delimitation between different practices of self-care that lead to freedom

and those that are repressive. Rather, the fate of our times may be that people are perpetually required to sort out this difference for themselves. There can be no formula. Although Foucault did not write specifically about health professional education, his theories induce scepticism about standardisations of practice in general. The dangers of any absolute and algorithmic prescription of practice probably outweigh the benefits of what such an exercise in power produces.

PIERRE BOURDIEU: HEALTH AS CAPITAL AND AS *ILLUSIO*

Foucault's contemporary and colleague, Pierre Bourdieu,^{15–17} offered a complementary version of practice theory, focused on people's core practices of acquiring and reinvesting diverse forms of capital. The fate of our times for Bourdieu was that the inter-generational transmission of privilege has become mystified, because privilege is less often transmitted in material forms, like property, or symbolic forms, like inherited titles. Instead, privilege is transmitted through complex investments and reconversions of capital; education is paramount, but health enhancements are increasingly relevant. The effect of these practices is to make privilege appear to be earned individually. Status is thus naturalised, inferiority is internalised as self-deserved, and resistance is rendered futile.

Those who study the medical complex, including medical education, from a Bourdieuan perspective ask, first, how *health* and education have become forms of capital in which it makes sense to invest. Doctors are trained to assist people in organising their investments in health. In the past, those investments have taken the form of fairly self-evident repair work. The development of cosmetic surgery after World War I¹⁸ marked a shift toward what can be understood as more constructive investments. Matters seem to be on the threshold of becoming more complex still. If the promises of genomics and so-called 'personalised medicine' come close to being realised, health will take on a qualitatively different meaning as a form of capital.

Let me move directly to an example that prepares for my later argument. Bourdieu may have been at his best when he analysed the academy. Whatever I want to understand about universities – hiring, budgeting or building – Bourdieu elucidated. Academia is, in Bourdieu's useful jargon, a *field* in which there are various forms of capital. For professors, forms of

capital include high scores on teaching evaluations, sizes of class sections taught, winning research grants, and different forms of publication. The boundaries of this field extend wherever someone recognises any of those as capital; if you encounter non-perception of the field's forms of capital, you have gone outside the field. Within a field there are different positions, which allow or restrict access to forms of capital. But the game is still more complicated.

Within a field there are also ongoing contests over which forms of capital have the highest valuation; for example, do teaching evaluations count in promotion decisions? As another example, does receipt of a research grant count as capital, or only the publications that result from the research? When I began my career, publication was the dominant form of capital and research grants were understood as having only instrumental value in enhancing chances for publication. Today, in Canada, there is a reward value even in failed research grant applications and I see official university biographies of professors who list the grants they have received and omit any mention of publications. That's a shift in the form of capital, and during my career that shift has taken place with remarkably little contest.

If Bourdieu's concept of *field* is the core of his theory, what I find most useful is his idea of *illusio*, which is not to be confused with illusion, albeit that Bourdieu understood demystification as a paramount goal of social scientific work. *Illusio* is a person's capacity to recognise what counts as capital in a field and, equally importantly, to take that form of capital seriously, which involves taking seriously the rules of the game by which that capital is acquired. To return to my former example, one of my limitations in the present academic field is that I lack the *illusio* for research grants. I simply cannot take them seriously as having inherent value. I cannot bring myself to make the investment in grants because the conversion value of capital gained seems to be primarily the capacity to win other grants. Thus to me, the process of acquiring research grants represents a distraction from what I value, which is thinking and writing. That *illusio* limits my participation in the contemporary academic field; my success is defined by what I can and cannot take seriously.

Health care is all about *illusio*: groups including practicing clinicians, administrators, policymakers, manufacturers, medical educators, medical students, and patients—among others—each have a stake in which happens, and each is able to take its own valued forms of capital more seriously than others

take that form of capital. Health care happens as it does because different groups have different capacities to make what counts for them count for others who do not initially share that particular *illusio*. Questions of who takes seriously which forms of capital play out in medical education over issues that include, but are hardly limited to, the hours of teaching time an academic doctor commands in a medical school, who gains membership on professional governance councils, how much financial income faculty staff derive from private practice, and how valued the gratitude of a few memorable patients is in the life of a doctor. Medical education, with its calculated overload of tasks and opportunities, models the doctor's future life as a series of decisions about the forms of capital that should be invested in and how the capital gained by those investments should be reconverted. A mundane but significant example concerns the time it takes to wash one's hands. Time is definitely a form of capital, and, to put it bluntly, sources of infection are hard to trace.

Medical students must also learn to recognise and accommodate the *illusio* of their patients; that is, what a particular patient perceives as worth taking seriously, or not. In the patient's *illusio*, what are the stakes of giving up smoking, changing diet, or agreeing to an invasive test? *Illusio* determines a patient's willingness to assume and even demand the risks associated with an invasive fertility treatment or a high-dose chemotherapy; it determines willingness to endure pain oneself or to inflict it on a loved one for the sake of an expected prolongation of life. As much as health care is all about power and knowledges, it is also all about *illusio*. Medical education should focus both on recognising the particularities of one's own professional *illusio* and, equally, on learning to work with the diversity of *illusio* presented by different patients and people with different roles in the education community (teachers, researchers, administrators and clinicians).

THE NARRATIVE TURN: HEALTH CARE AS STORYTELLING

Let me summarise my review with a comment about my own work, which is a version of narrative medicine.¹⁹ For about 25 years, I've been studying how people express their experiences of illness and health care in stories they tell, principally stories that are published.^{20–22} By contrast with Parsons, I understand sickness and clinical practice not as roles, but as constant struggles to make meaning. Stories are

a primary medium through which humans make meaning communally.

From Garfinkel, I understand storytelling as a form of work, in which the incoherent is rendered coherent. When we turn other people into characters in our stories, we render their actions sufficiently comprehensible to keep our reality coherent; even evil characters are comprehensible as evil. We tell stories about ourselves to others, first and foremost, so that we – the choices that make up our lives – will make sense to them. One aspect of being such necessarily social animals – beginning with our prolonged infantile dependency – is that we humans desire to make sense to other people. More complex claims are built on that.

From Foucault, I understand storytelling as a practice of care of the self that is both productive and dangerous. Storytelling produces a world worth living in, and it produces the sense of a character it is worth the effort to be. However, producing that world is dangerous. Because any story is always mostly borrowed, there is an inherent danger that we will require ourselves to act as a character whose motives and desires are prescribed by others. Another danger is that narrative form requires antagonists, which often means others must be recruited to play those roles. Finding enemies to fit the needs of a story that requires enemies is dangerous for both the narrator and those cast as enemies.

From Bourdieu, I learn to recognise which particular stories have taught me what the stakes of the game are and which stakes I ought to take seriously. Life chances depend crucially on the particular stories we know and can take seriously. Stories are the medium in which my *illusio* is formed and reformed. In Bourdieusian terms, storytelling is *illusio* work: it involves both the attempt to reflectively grasp one's own *illusio*, and the mutual work of harmonising different *illusio* sufficiently to get on with life lived together.

One implication of thinking about stories this way is that most conflicts in the medical complex can be understood as narrative conflicts. Sometimes the conflict in the narrative concerns point of view. Which character's perspective becomes the story's primary point of view as it is told determines whose *illusio* listeners are conscripted to accept as self-evident. Other conflicts concern genre, especially Northrop Frye's²³ distinction between the low-mimetic and apocalyptic genres. In the low-mimetic genre, character distinctions are minimal, actions are

mundane and problems are negotiable. In the apocalyptic genre, characters are polarised and action moves inexorably toward a final confrontation between good and evil. Front-line medical workers tell themselves stories in a low-mimetic genre; for them, these things are everyday occurrences. But patients and their families feel they are living in an apocalyptic story; how they act in this crisis defines their lives. The sorts of practices that are expected of characters in one genre would represent moral failings were the story to be understood in a different genre. If medical students could think genres as readily as they think diagnoses, much conflict would be prevented.

My own sense of the fate of our times is given a fine epigraph by Salman Rushdie, who, in this instance, I consider genuinely prophetic: 'Everywhere is now part of everywhere else. Our lives, our stories, flowed into one another's, were no longer our own, individual, discrete. This unsettled people. There were collisions and explosions.'²⁴ As often happens in the history of ideas, we have discovered that identity takes a narrative form at the moment when it becomes more difficult for more people to understand their lives as cohesive stories.

In the illness–health–medical complex, one group's stories flow into another's. More doctors write about their own illnesses, and more patients claim medical expertise in online groups. People are desperate for stories they can call their own because the medical complex chews up individual identities. Institutional medicine manages the extraordinary feat of homogenising people while reproducing and accentuating inequalities between them. As competition for capital intensifies – both in medical school activities and in the provision of health care services, each of which impinges on the other – the collisions and explosions will become louder and more frequent. How is the social scientist to respond? How can medical education as a field take advantage of the insights derived from such responses?

CRITIQUING THE SCARCITY LOOP: A TENTATIVE CONCLUSION

Medical education must prepare doctors to encounter the endemic contradiction in health care between the hopes, desires and expectations that capitalist techno-science thrives on generating, and the realities of what can be delivered and who can afford what. A shorthand term for this contradiction is the *scarcity loop*, in which demand always exceeds supply, and the perception of excess demand justifies multiple

exclusions and disciplinary practices. I hear all the discourses in the illness–health–medical complex participating in the scarcity loop. Curriculum discussions presuppose scarcity of time and the size of the graduating class enacts the future scarcity of doctors. The fate of our times, at least with respect to health, seems to depend crucially on how we – those who offer medical services and those who need them – position ourselves with respect to the scarcity loop; there seems to be no evading it. I propose that the task for social science is to refuse to treat the scarcity loop as inevitable and instead to critique the effects of positioning *scarcity* as the premise of virtually all health care decision making.

The theorists I have discussed do not provide a ready formula for thinking outside the scarcity loop – again, they argue against such formulas – but they can help us to ask how particular health care practices are formulated on the assumption of scarcity, and what that assumption rationalises. They help us to recognise how specific practices – like failing to wash one's hands – are enabled when those who do such things frame their acts within the scarcity loop. Here I fall back on the faith common to both Foucault and Bourdieu, that reflective awareness is the beginning of opposition and, eventually, of imagining an alternative.

My argument in this article does not depend greatly on whether I am right about the scarcity loop and its effects. Right or wrong, my remarks can serve as a model for thinking about the fate of our times and for framing health care questions within those issues. Of course, a great deal more could be said about who benefits from the presupposing of scarcity and who pays what price when discussion is framed by such assumptions.

I have told you a story about social theory in the second half of the 20th century and suggested that research should link its specific questions to broader considerations of the fate of our times, however you understand that. I am arguing for theory-grounded research. My worry is that the shifts in academic capital to which I referred earlier – from publication capital to grant capital, and within publication capital, increasing emphasis on short-term reports – make it well near impossible to invest in the duration and intensity of *thinking* that Parsons, Garfinkel, Foucault and Bourdieu did, which required considerable institutional support and, it's important to emphasise, institutional patience and trust. Of more immediate relevance to medical education is the risk that research and policy planning that do not utilise

the insights of these thinkers will isolate themselves from the historical conditions that produce the problems with which specific institutions grapple. Of course these theories must be refined and, over time, changed; some may be best disagreed with, but at least that disagreement inspires thinking outside conventional parameters.

I want to close with a quotation from Foucault which suggests the possibility that the demands of critical self-reflection can be reconciled with the practical need to go on working in conditions that will not change tomorrow or next year:

‘We need to escape the dilemma of being either for or against... Working with a government doesn’t imply either a subjection or a blanket acceptance. One can work and be intransigent at the same time. I would even say the two things go together.’¹³

That statement can free medical educators to meet the multiple demands of accreditation reviews, budgets and time constraints, while sustaining their own recognition of what their students need to learn. We academics especially are freer than we believe ourselves to be. However, if we cannot convince ourselves of our freedom, we will probably fail to convince anyone else of theirs, and if that were to happen, I am not sure what good we could do as educators, or what good practising doctors could do as healers. You might notice that I want freedom to be a central component in any definition of health.

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