

Disclosure in Health and Illness

Edited by
**Mark Davis and
Lenore Manderson**

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7 Disclosure as method, disclosure as dilemma

Matthew Wolf-Meyer

I heard of Jack during a grand rounds meeting at the Midwest Sleep Disorder Center (MSDC), where he was presented as a case to the assembled doctors, technicians and staff. Dr Richards, the senior staff neurologist, narrated the case. Jack was a white man in his mid-fifties, who had first experienced symptoms related to narcolepsy in his late thirties. At the time, he assumed that his daytime fatigue was related to stresses at work, and he would often contrive ways to sleep in his office or in his car in the parking lot. When he awoke, he often experienced hypnagogic hallucinations, and so he ensured that he never had to wake up quickly to attend to a workplace demand. He would also often wake up in the middle of the night and find it difficult to return to sleep. At first he assumed this had to do with his daytime naps, so he tried to stop napping during the day in order to consolidate his sleep at night. He found his caffeine consumption during the day quickly increasing, but this strategy did not seem to work. His most worrying complaint was his experience of cataplexy, the sudden loss of muscle tone, which caused him to lose his grip on things he was holding, or to fall down while walking. These bouts were brought on in periods of heightened emotion, usually when Jack was laughing with a colleague or friend.

In many ways, Jack's case is unexceptional for a narcoleptic. What was exceptional – and the reason why Dr Richards was presenting his case – was that Jack was a heart surgeon in the hospital that housed the MSDC, and the attending staff, comprised of physicians, research scientists, nurses and technicians, were being presented with an ethical dilemma: Should they reveal to the administration that one of the doctors on staff was a narcoleptic?

Jack had hoped the doctors at the MSDC would prescribe him medication that would alleviate his narcolepsy symptoms, but that this would be masked as medication for other syndromes. Narcolepsy, although very treatable with the current pharmaceuticals used for it – modafinil to promote alertness and Xyrem to consolidate sleep and relieve cataplexy events (Wolf-Meyer 2009) – carries a social stigma, and public knowledge that Jack was receiving this medication would place him into a high risk category for his medical malpractice insurance. The conversation that followed Dr Richards' presentation

of the case was fairly charged – the physicians understood what was at stake for Jack, and sympathised with their peer. But they were equally worried about their field. What if a narcoleptic, using drugs off label, were to commit malpractice? The negative publicity would surely impact on them and they might be legally culpable. The debate reached no resolution, as was Dr Richards' intention in presenting it to the group: he considered the case as an exercise in ethical thought.

I reflect herein on the role of disclosure in ethnographic writing and the ethics that limit the possibilities of full disclosure. My interests are similar to those of Dr Richards: the use of disclosure as the basis for thinking through ethical problems. To discuss the act of disclosure from an ethnographic perspective, I present the same two cases from my research on sleep in the United States (Wolf-Meyer 2012) at increasing levels of fictionalisation. That is, taking a page from late modernist fiction,¹ I present the same two cases three times each with each presentation more fictional than the last – increasingly removed from the empirical situation I originally describe – enabling me, therefore, to disclose more about the cases. As the ethnographic cases become more fictional, I am able to disclose information that would be incriminating or troublesome if these details were presented in the more factitious versions. But, even as I foray into fiction, the presentations continue to borrow from fact, that is, the facts of the cases discussed and facts about sleep and its history in the USA.

I am interested in the tension between ethnographic verisimilitude and facticity precisely because it lies at the heart of ethnographic writing (Clifford and Marcus 1986), and exists in institutional tension – between social scientists and their institutional review boards, between researchers and their informants (Brettell 1996), and between writers and readers (Iser 1978). Thus, part of my intent here is to think through the act of disclosure in ethnographic writing as a methodological concern. Secondly, and this is the motivation for my interest in these discursive acts of disclosure, in this chapter, I attend to the institutional and material consequences of disclosure. For both Jack and Ryan, whose experiences I discuss below, the consequences of their disclosures endanger their status as employees and, by extension, their ability to meet their family obligations and other social commitments. Their differential abilities to disclose their conditions in their workplaces impact on my own ability to discuss their cases, as information of their cases could lead to the possibility that co-workers, family members and social acquaintances might identify them beyond their pseudonyms, leading to workplace difficulties. This might be unlikely – we all write on the assumption that a lay reader is unlikely to come across this chapter and follow the cases, and to make inferences about the individuals they know – but the shadow of this possibility limits my ability to make ethnographic disclosures, precisely because it may have material consequences for the individuals involved. Central to modern institutional review board (IRB) and human subjects guidelines in the United States, like ethics committees elsewhere, is the

assumption that the disclosure of the health status of individuals – particularly regarding disability – may have employment consequences and unintended social ramifications for the depicted individual if readers can work through the data to discern the individual's identity, however unlikely that may be. Nonetheless, modern ethnography has accepted this risk, leading to the slightly fictionalised forms that ethnographic writing is now marked by. I am interested here in the ethics of ethnographic disclosures – what might be said and what may not be – and the constellations of knowledge that this produces (Faubion 2011).

These problems of representation in ethnographic writing have been continuing concerns in anthropology from the 1970s (Hymes 1974) and particularly the 1980s, when critical attention to social science claims of objectivity resulted in a move towards reflexivity regarding the situated knowledge production of the ethnographer (Clifford and Marcus 1986). The most lasting impact of Clifford's and Marcus's critiques of ethnographic writing in *Writing Culture* (1986) may be the conventions that ethnographic writers now incorporate into their writing to make their work more 'novelistic'. That is, rather than the presentation of demarcated social realms (e.g. Evans-Pritchard's discussion (1940) of Nuer religion, kinship, political ecology, etc., as properly isolated from one another), contemporary ethnographers are more likely to integrate these social forms into discussions of events, life histories and everyday action – usually associated with a theme identified by the author (for three very different cases, see Biehl 2005, Bourgois and Schonberg 2009, Das 2006). One might conceptualise this mode as relying more extensively on the disclosure of the ethnographer about what he or she claims to know and less upon acts of disclosure on the part of his or her informants about their experiences, which may trouble the veracity of the ethnographic text, but is necessary if ethnography is serving as a mechanism of social critique (Marcus and Fischer 1986). Ethnographers are now resolutely part of their texts (see, for example, Helmreich 2009, Martin 2007); this might be taken as evidence that the critique of objectivity lodged by Clifford and Marcus, and their collaborators in *Writing Culture*, has profoundly changed the art of ethnography and its aims. Central to these changes, I argue, is the place of doubt in the production and interpretation of ethnographic texts; this doubt is rooted in the performance of social scientific authority on the part of authors and the interpretive strategies of readers, both of which depend upon the understanding of acts as disclosure, fictionalisation and concealment as integral to ethnography.

These concerns about representation, subjectivity, fiction and truth are indebted to trends within literary and cultural studies, now quite far removed; however, it is worth returning to Eric Auerbach's discussion of mimesis in literary writing (2003 [1953]). For Auerbach, modernist writing, which social science writing is surely part of, is indebted to the 'realism' he attributes to biblical writing, as divergent from the 'rhetorical' writing associated with legend. Auerbach characterises realist writing with these

qualities: 'Certain parts brought into high relief, others are left obscure, abrupt, suggesting influence of the unexpressed, "background" quality, multiplicity of meanings and the need for interpretation, universal-historical claims, development of the concept of the historically becoming, and preoccupation with the problematic' (Auerbach 2003 [1953]: 23), which might also be read as an apt description of contemporary ethnographic writing. Leaving aside the relationship between Christianity and contemporary social science (Cannell 2005), the struggle for verisimilitude on the part of ethnographic writing is intended to both convince the reader of the author's experience, as well as those experiences of others that the author is representing to the reader. The basis for the author's argument and, by extension, the basis for critique, is founded on a scientific, mostly objective understanding of the conditions being reported, however contrived or bracketed these conditions are (Haraway 1997, Shapin and Schaffer 1989).

But what if ethnographic writing hewed more closely to the rhetorical, the discursive production of fiction? Auerbach describes the quality of rhetorical literature in the following way: as a 'fully externalized description, uniform illustration, uninterrupted connection, free expression, all events in the foreground, displaying unmistakable meanings, few elements of historical development and of psychological perspective' (Auerbach 2003 [1953]: 23). While some contemporary ethnographic writers employ some of these tactics, very few social scientists use all of them: this self-imposed limitation is based upon the author's desires to be seen as making scientifically sound claims (see, for example, Taussig 1997). However, the rhetorical opens up a number of possibilities for the presentation of ethnographic data, not least among them the ability of estranging the reader. For Darko Suvin (1979), and later Fredric Jameson (1991), realism is important precisely because it can be subverted; the power of most science fiction and 'postmodern' literature is that it is first able to convince its reader of the reality being described, and then is able to subtly – and sometimes radically – unsettle the reader's conceptualisation of reality. By doing so, the reader's reality becomes destabilised and the applicability of the text – its interpretive latitude – becomes greatly expanded. Like ethnographic writing, acts of disclosure often traffic in the language of the real. They must appear 'real' or based in truth in order to be full disclosures. But might more rhetorical disclosures ('I have a friend with a problem . . .') produce similar or even more profound effects, both for the discloser and his or her audience?

Knowingly skirting the conceits of realism allows me to momentarily present my ethnographic bona fides. From January 2003 through April 2007, I conducted archival and ethnographic research, first in the Twin Cities in Minnesota, and then in Chicago, Illinois. The research began at the pseudonymously named Midwest Sleep Disorder Center (MSDC), where I would attend weekly case discussion meetings and departmental lunches, as well as visit the overnight sleep clinic. I conducted formal and informal interviews with clinicians, researchers, patients and their families at the clinic

and throughout the Twin Cities. At the same time, I attended local support groups for individuals diagnosed with obstructive sleep apnea and restless legs syndrome, and conducted archival research at the Wagensteen Historical Library of Biology and Medicine, housed at the University of Minnesota, and containing medical monographs from the nineteenth and twentieth centuries. In February 2006, I relocated to Chicago to conduct further research: archival research at the Special Collections Research Center at the University of Chicago's Regenstein Library, and ethnographic research with patient support groups throughout the Chicago Metro region. Coextensive with these two in-depth field research periods, I attended local and national professional meetings for sleep physicians and researchers, as well as national support group meetings for less common sleep disorders, especially narcolepsy. Over these three-and-a-half years of research, I informally interviewed more than eighty disordered sleepers, and conducted life history interviews with an additional forty. In addition, I conducted interviews with a dozen sleep clinicians and researchers, some affiliated with the MSDC and others not. I also interviewed sleep technicians, nurses and the family members of disordered sleepers.

In *The Slumbering Masses* and related articles (Wolf-Meyer 2008, 2011, 2012), I have written extensively of intimacy as a way to conceptualise the relationships between individuals and their therapeutic treatments and the doubts that exist between physicians and the science of sleep. Herein, I want to think about these two concerns as discursive and related to the ethnographic representation of cases, operating first between interviewer and interviewee, and secondarily between author and reader. In the case of intimacy, I am interested in how relationships between individuals and material objects and processes alter the capacities of each; as we open ourselves up to the agentic qualities of pharmaceuticals, prosthetics, institutional demands and social relations, our bodies are likewise reconfigured. These subtle reconfigurations of our selves allow for further intimate transformations between our bodies and our environments. Physicians often use vagueness and opacity in the scientific and medical literature to manipulate data to provide alternative explanations for empirical realities; doubt allows for the re-diagnosis of a patient's case, possibly with better therapeutic results. I want to play with doubt as a discursive strategy. For most ethnographic writing, the straightforward presentation of evidence is a technique to allay doubt. It is meant to be convincing in its support of argumentation. But what if doubt is produced in ethnographic writing in order to broaden interpretive possibilities for readers? Doubt might be used analogously to Marshall McLuhan's discussion (1994 [1964]) of 'hot' and 'cold' media to unsettle the authority of the text and reauthorise the power of the reader to make interpretive claims. More abstract presentation of cases might move social science beyond 'cold' texts and towards arguments that move beyond the historical and spatial limitations of the original study. I return to these claims by way of conclusion. I turn first to the initial

presentation of Ryan's case, and then represent Jack's and Ryan's cases in the sections that follow.

Disclosure and consequence

When I interviewed him, Ryan had been diagnosed with almost all the conditions that a disordered sleeper could be diagnosed with: narcolepsy, REM (rapid eye movement), behavioural disorder, obstructive sleep apnea, shift work sleep disorder, and a vague circadian rhythm disorder. Despite exhibiting symptoms since childhood, he had decided at age 40 that something might be physiologically wrong with him. And it was only at 48 that he finally sought out diagnosis. At the time of our interview, in his mid-fifties, and inching towards retirement, Ryan had some control of his sleep through a mixture of pharmaceuticals, CPAP technology (*continuous positive airway pressure*) and social arrangements of his working time. 'I work a twelve hour shift,' he told me, 'from six at night until six in the morning, or from six in the morning until six at night.' He is employed by a large power company on the East Coast, working to maintain the integrity of the power grid of a large metropolitan area. His workday consists of him sitting in front of a console for hours at a time, with little change in activity or object of focus. This is dull work, but within his unionised labour force, it is a sought-after position since it does not involve handling any electrical equipment and is therefore not life-endangering.

Because of his various sleep disorders – and workplace problems he narrates presently – at work, he takes Provigil, an alertness-promoting drug. He goes on to explain not only his work situation, but how it renders his sleep as disorderly:

The longest one shift goes is four days, and then I shift to the nights. And I can have one day off in-between, or eight days off in-between . . . And then there's one week when you have to work relief, where you have to work four hours in the morning, then twelve hours that night, and twelve hours the next day, so my biggest problem is 'when do I take my medication'. If I have to skip it, then I'm more of a zombie . . . I took a letter from my neurologist that said that I need to take a midday nap on each shift, and they sent me home for three weeks without pay while they figured out what to do. They brought me back and said, 'If you take a nap, you're fired.' And this is a company with 12,000 employees. And then I took a letter in that said that if I continue to work without napping, I could endanger myself or others, and with that one they sent me home for three months . . . I was on 'crisis suspension', so I got paid for that one . . . My personal feeling is that they don't want anyone to have any kind of personal accommodation or anything because it will open up a can of worms. [My sleepiness was] troublesome when I was a kid, but the older I get, the harder it gets.

'How do you cope with it?' I asked. 'Napping, and working an eight-hour shift. I think napping works. But my employer treats napping as a personal choice, so that means it's a conduct issue. That's what they believe right now.' Ryan is caught in an especially difficult situation: whether or not he expressly discloses his condition to his employer, his behaviour and workplace performance may lead his managers to suspect some problem. The choice he is faced with is an explicit disclosure of his condition, which may result in workplace discrimination of some sort, or an implicit disclosure through his ongoing workplace behaviours, which may also lead to consequences, but without legal recourses available.

Disclosing their conditions to their employers entails consequences for both Ryan and Jack, in each case shaping both the possibilities of their work lives and their lives beyond work. This limits Jack's ability to make his disclosure, as his secrecy allows him to pursue his profession as he desires; admitting his condition to his supervisors would lead to his immediate dismissal or, at best, a curtailing or transformation of his workplace roles, that is, he would be removed from performing operations. The indignity that this would lead to would be tantamount to Jack not working at all, so foreclosing the possibility of admitting to his condition. Ryan does disclose to his employer the nature of his condition and the medical recommendations that could support his ongoing participation in work but, in consequence, he immediately faces disciplinary action, not for his behaviour, but for the affordances he will require as an employee with special dispensations. Ryan is removed from the workplace, albeit temporarily, so that his employers can ascertain the consequences of making allowances for his workplace requirements. His is eventually given eight-hour shifts, but he still sneaks out to his car during lunch breaks to take a nap, a compromise that at once treats him like other employees – he will be disciplined if caught napping – and different, as he is only given eight- (rather than twelve-) hour shifts.

The differences in Jack's and Ryan's abilities to disclose their conditions to employers are more an effect of narcissistic attachment than an effect of perceived consequences, although they are clearly entangled with one another. For Ryan, his job is just that: a job. He has risen through the ranks to a position of seniority, is protected by his union, and is waiting for his eventual retirement. Reaching retirement with full benefits is the one fear that his disclosure skirts, but he has his union to protect him from being summarily dismissed. For Jack, the story is different. His attachment to his career extends beyond his position, and it is tied to his understanding of himself as a specialist, extremely capable at what he does: the loss of his job would not simply affect him, but would affect his potential, future patients, who may fall into the care of a less capable heart surgeon. Jack's notion of his standing among his peers may be fanciful, but it is enough justification for him to seek out his colleagues for private consultations, especially when compounded with the most likely outcome of what may happen to him if he were to disclose his condition to his supervisors. Secondarily, his decisions

about his career will impact on his family and the lives of those he cares for in a non-professional manner. Part of the difficulty of these disclosures, however, is that despite there being treatments for narcolepsy and other sleep disorders, there is also the acceptance on the part of physicians that none of these treatments is so effective as to render disorderly sleepers into perfectly and predictably orderly ones (Wolf-Meyer 2009).

Elsewhere, I have suggested that contemporary American medicine is characterised by its reliance upon therapy, that is, it depends upon regular, incomplete interventions on individuals in order for the individual to retain a sense of normality and orderliness (Wolf-Meyer 2014). This model of intervention stands in contrast to ideas of cures, which offer one-time, complete resolution of symptoms. While a cure offers the promise of returning an individual to a pre-symptomatic state or a new normality, therapies require constant negotiation between patients and physicians, individuals and treatments (pharmaceuticals, prosthetics, etc.), and between an individual and his or her social obligations. Therapies can change over time, lose effectiveness or become compromised by parallel prescriptions: in so doing, they always risk becoming ineffective. And because therapies are incomplete in their resolution of symptoms, there is also always the possibility that an individual will miss taking a pill or other temporary treatment, resulting in the full return of symptoms. This is part of the underlying problem for both Jack and Ryan. While treatments exist for their disorderly sleep, they are not cures and cannot return Jack and Ryan to normality in a resolute fashion. Instead, for Jack and Ryan, only temporary relief exists, and they will have to risk the possibility of missing a day's medication or the failure of a treatment to prove effective in a time of need. Their conditions are risky for what they might entail in the future, threatening their own and others' lives and wellbeing.

Disclosure once removed

Jack was a test pilot; his professional life has been stressful and competitive. Graduating from university, Jack enlisted in the US Air Force, flying missions in the first Iraq War in the early 1990s. At the time, Jack would experience brief dizzy spells at takeoff, which he came to attribute to lightheadedness associated with the dramatic speeds and changes in altitude he was experiencing. He never talked about it with anyone. When he wasn't flying, Jack would find himself dozing through the day, attributing his perceived laziness to the stresses associated with flying manned missions over a warzone. To offset his drowsiness, he would routinely drink a pot's worth of coffee before and after lunch, cup by cup. But rather than feel wired by the caffeine, Jack still struggled to stay awake. Only during operations did he really feel most engaged with the world around him. Jack came to think of himself as an adrenaline junkie, really only alive when he was under stress and defying death in one form or another. Returning from Iraq, Jack enrolled

in martial arts classes, began rock climbing, and found a job for a large military research and design company that specialises in experimental aircraft design. After more than a decade of flying new stealth bombers and fighter jets, his employer offered Jack the opportunity to test its next-generation space shuttle, a low orbit passenger plane intended to ferry high-paying passengers to the edge of space. Leading up to this opportunity, Jack began to realise that what he had convinced himself of – his status as an adrenaline junkie – was a polite fiction which protected him from the reality of his condition. One night, at home on a Sunday, he watched an episode of *60 Minutes* with an interview of a noted neurologist who specialised in sleep-related disorders. One of the patients interviewed was a narcoleptic who narrated his symptoms, which aligned perfectly with Jack's own. Consulting with his family doctor, Jack came to understand that the likelihood of his being able to be medicated for narcolepsy and fly was unlikely, if not impossible. But rather than disclose his condition to his employer, Jack decided to pursue a position in the flight simulation facility, training the next generation of pilots to fly drones and jets in emergency situations, never needing to admit his condition to his employer.

Ryan is a police officer in a medium-sized city on the American East Coast. 'I work a twelve hour shift,' he told me, 'from six at night until six in the morning, or from six in the morning until six at night.' He went on to explain: 'The longest one shift goes is four days, and then I shift to the nights. And I can have one day off in-between or eight days off in-between . . . And then there's one week when you have to work relief, where you have to work four hours in the morning, then twelve hours that night, and twelve hours the next day.' Like many Americans who work shift-work schedules – where they change their work shift from week to week in an effort to maintain some kind of egalitarian sharing of the misery relating to night work – Ryan experiences a number of symptoms that his family doctor refers to as shift-work sleep disorder. That is, Ryan experiences insomnia when he has the time to sleep, and sleepiness when he should be awake – even when he's working during the day. Protected by his union, Ryan cannot be fired from his position on the force, but that does not make his work life any easier. In some respects, it makes it more difficult. If the union was not involved, his seniority would not prove so difficult to manoeuvre, and he might be able to be moved to a less desirable desk job. But, as it is, Ryan is poised to retire in a few years. And, although Ryan knows that those few years will be long ones, he consoles himself with taking naps in his patrol car, as long as his partner manages to stay awake.

Discussing Jack's and Ryan's cases raises questions for ethnographic depictions of individuals in risky situations, particularly those where the lives of others are the ones being endangered. The closer my representation of their cases is to the evidence, the more likely I am to provoke the very consequence that they fear. Even in their first presentation, I abide by contemporary ethnographic practice and render each with pseudonyms and

remove identifying information about their actual workplaces. Although it has been several years since they were originally interviewed, and in both cases solutions have been reached by Jack and Ryan and their supervisors, there is still the possibility of some sort of backlash against them by those who might identify them: at least this is the assumption of institutional review boards (IRBs) that approve ethnographic research only when it meets standards in obscuring the identity of respondents. But there is a potential problem here: at least in Jack's case, I was privy to information that could affect the lives of patients, and was ethically bound to not disclose the situation I had observed. By presenting Jack's case to me – among the other staff at the sleep clinic – Dr Richards made me as culpable as the rest of his colleagues. Although a solution to the problem was in the offing without my knowledge, the presentation of the case immediately raised ethical concerns for me, although these were summarily suppressed by the strictures of the IRB approval I laboured under. That is, the IRB approval I already had meant that I need not bother with the ethical quandary: the decision of keeping silent (or at least obscuring the identity of the actors) had already been made for me. Should I be exempt from ethical quandary?

My knowledge of Ryan's sleep disorders might have led me to contact his employer, particularly if I felt that the recommendations he had already been given by physicians were insufficient. In Ryan's case, as much as Jack's, lives were at stake. For Jack, it was the patients before him on the surgery table. For Ryan, it was anonymous citizens, who, during times of emergency, might be at risk. But, again, I was removed from the ethical problems associated with these disclosures, protected by the IRB. Similarly, you, my reader, are exempt from these ethical considerations. If you could infer the identities of these two men, you might be put into the position of disclosure on their behalves. And as my representation of these two cases becomes more fictitious, more abstract in relation to the original evidence, the more likely it becomes that you are able to apply the cases to those around you. Maybe Jack the doctor and Ryan the power company worker are far from your social circle – and maybe so are Jack the test pilot and Ryan the police officer – but the further I remove them from their original situations, the more open the interpretive possibilities become. Maybe Jack was not a doctor at all, nor Ryan a power company worker. Maybe those representations were already fictitious, once removed to preserve Jack's and Ryan's identities and lives.

Tertiary disclosures

Jack is a German Shepherd. He is the great-grandchild of German Shepherds who were bred at Stanford University Sleep Disorder Center to test the genetic prevalence of narcolepsy. All of Jack's great-grandparents, grandparents and parents experienced narcolepsy symptoms; in their relatively comfortable lives at Stanford's laboratory cum dog ranch, this family of dogs

was susceptible to spontaneously falling asleep when excited. Play would often turn into a cascade of napping dogs. Dinner time would often become a comedy of errors as technicians prodded dogs awake to eat the meals so eagerly anticipated. Even casual affection for a dog could result in it dozing off at the feet of its caretaker. Jack was no different, prone to falling asleep at times of heightened emotions. What was different about Jack was this: he was born outside of the laboratory, the first generation of dogs born after the research had been decommissioned. How many generations of narcoleptic dogs do you really need to breed to see the hereditary component of narcolepsy, after all? And so Jack lived his life off-campus. But he was precluded from certain kinds of jobs a dog of his breed might do: no sentry work, no actual shepherding. Instead, Jack was adopted into a nice, suburban family living in nearby Woodside, where he spent most of his days lounging on the back porch or family room couch. Jack's genetic legacy haunts him, however innocuous it might seem. On Wednesdays, when the garbage trucks scour the neighbourhood, Jack rises to bark at them, but quickly lapses into sleep amid his excitement. When the school bus approaches the corner on which the children in the family disembark, Jack often falls asleep, overcome by his excitement at seeing the kids. Jack's human family understands his limitations, and while Jack's being overcome with sleepiness might perturb police officers or farmers who employed him, his suburban family is content with a dog they sometimes find humorous in his excitement turned into spontaneous napping.

Ryan is a physician, a heart surgeon, who practises at a large teaching hospital associated with a nearby university in the American Midwest. When he's attending, he works long days, often twelve hours, but regularly upwards of eighteen, as he tends to take his work home with him and is never far from being able to be called in during an emergency situation. In some respects, Ryan is always on call, burdened by his sense of being the most capable heart surgeon on staff. Even at weekends, he's likely to respond to calls from colleagues, and he hasn't taken a vacation in nearly a decade. But Ryan lives with a great deal of anxiety – having a bundle of sleep-related disorders – and he lives in fear that these will be discovered by his colleagues, patients and administrators. At first he thought his excessive daytime sleepiness was simply the result of his long hours of work. He imagined his intermittent insomnia to be related to stresses associated with work and thought his weight gain and laboured breathing during sleep to be an effect of his slowing, ageing metabolism. But as the science and medicine of sleep matured over the 1990s and early 2000s, he saw a number of patients with disorders similar to his own and came to realise that he too was a disorderly sleeper. If he were to reveal his condition to his supervisors, colleagues or patients, he would surely be barred from performing the surgeries he felt so superior to his colleagues at performing, that he felt so defined him as a professional.

Ryan consulted with one of his colleagues – a neurologist also on staff at his hospital – who he imagined would keep his confidence on these matters. What, Ryan asked, could be done to alleviate his symptoms but allow him to work as he had for the past twenty-five years of his professional life? His colleague, Dr Richards, suggested that he deliver a letter to the administrator who oversaw the pulmonary care department at their hospital, which Richards would prepare with recommendations that would ease Ryan's symptoms without disclosing the nature of his sleep disorders. Richards and Ryan collectively hoped that this tactic would provide the administration with 'plausible deniability' related to Ryan's condition, but would also facilitate Ryan in his professional goals and personal desires for sleep. Ryan reported to me:

I took a letter from my neurologist that said that I need to take a midday nap on each shift, and they sent me home for three weeks without pay while they figured out what to do. They brought me back and said, 'If you take a nap, you're fired.' And then I took a letter in that said that if I continue to work without napping, I could endanger myself or others and with that one they sent me home for three months . . . I was on 'crisis suspension', so I got paid for that one . . . My personal feeling is that they don't want anyone to have any kind of personal accommodation or anything because it will open up a can of worms.

Doctors have always had the ability to take naps during slow periods of a shift, but what Ryan was asking for was a more bureaucratic dispensation that would allow him to nap even during busy times at the hospital. The administration was unwilling to grant this request, and was infuriated by his collusion with Richards. After conducting an investigation, the hospital offered Ryan the opportunity to retire early, move into administration, or be dismissed. Unable to conceive of a life without work, Ryan moved into administration, far removed from patients, and was able to sneak the occasional nap on the couch in his office into his daily schedule of supervision and meetings.

One way to assess the damage that more fictive representations create is to assume that as the gyre of representation widens, so does the doubt produced in the reader by the text. The gap between fact and fiction that this kind of more fictive presentation creates may disrupt the vital intimacy between author and reader by disturbing the reader's sense of verisimilitude. What if I were to tell you that the first presentation of these cases was the most fictionalised and this last presentation the most factual? Ethnographers often toy with their evidence, changing names and locations: a modest fictive art that readers collectively accept as part and parcel of protecting informants. Ethnographers also render many people into composite characters, sometimes mixing experiences and evidence between two or many real

people to tell a more cohesive tale: again, a fiction meant to protect the identities of the many involved. But what is the limit of fiction that a reader might be willing to allow in an effort to elicit the truth of the matters at hand?

Throughout the permutations of Jack's and Ryan's stories, some commonalities remain, particularly the nature of their sleep complaints. That is, I maintain my interest in sleep and its relation to American society, particularly as it makes work especially difficult for Jack and Ryan. But might the story be told otherwise to achieve the same ends, might my ethnographic disclosures be bent further to more fully explore the ethical quandaries of Jack, Ryan, those around them and myself?

The risk in these permutations is that they unsettle my authority and your ability to believe in the cases themselves. Although it is rarely discussed, suspension of disbelief is not something usually attributed to the reader of social scientific writing. We assume implicitly that the events, people and places we read about are real, although we might grant leeway in their representations for ethical considerations. Ethnographic acts of disclosure, particularly of the kind that I present in the introduction to account for the empirical basis for my research and argument herein, are widely accepted as necessary conventions of social scientific writing. As readers, we want to believe the facticity of what is presented to us, although we may question its representativeness or the rigour under which the research was conducted. Breaking from these conventions – not presenting these kinds of background conditions or disclosing too much about one's state of mind or concerns (Behar 2003 [1994], Briggs 1971, Favret-Saada 1981) – is likely to provoke questions about the veracity of the research. That is, too much disclosure on the part of the ethnographer may call into question the ethnographer's ability to faithfully represent what he or she has witnessed, however situated that knowledge is acknowledged to be. But, breaking from these conventions may equally help to ethnomethodologically unsettle the frames of ethnographic writing to the point that the intimacy we desire in our reading practices makes room for the interpretive latitude of doubt we may need to use ethnographic representations of cases in our own lives. The more doubt a text produces, the more applicable it becomes for readers who approach it from different contexts than that of the author; in order to make my discussions of sleep disorders and their complications meaningful to those outside of the world of sleep, some abstraction, some fictionalisation is required. And even for those who are intimately involved in sleep, too literal of a presentation of data means very little – some interpretive room is required to see ourselves in other worlds. A little more doubt may lead to greater textual intimacy, at once asking the reader to interpret the text at hand, but also providing the reader with tools to use in her or his engagement with the world beyond the text.

Disclosure as method

I know a man who drinks the equivalent of three pots of coffee each day. He stretches it out over the course of the day, but he drinks it nonetheless. If you believe that claim, it probably has to do with my demonstrating my sleep expertise throughout this chapter. But if I were to tell you that it was six pots, would that be believable? Would twelve? As Manderson points out in her introduction to this volume, the storytellers, the disclosers, are often put into a position of vulnerability; they are open to claims on the part of their interlocutors about the truthfulness or accuracy of their disclosures, as well as being subject to their interlocutors' reactions to what has been disclosed. Some of the artifice of ethnographic writing – like discussions of sample size, method and the use of generic conventions around the presentation of evidence and the kinds of evidence deployed – are meant to mitigate these vulnerabilities. Despite often trafficking in extreme and exceptional cases, ethnography tends to be accepted as a credible act, a method that defrays potential disbelief in the cases it presents. Across worlds and experiences that might be very alien to its readers, ethnography gains its power by revelling in the mundane as much as exposing the exceptional. This pairing of the mundane and the extraordinary depends on the use of the realist conventions that Auerbach outlines in the presentations of data: the extraordinary might seem impossible if not for an ordinary foundation. Although ethnographers are exposed to the vulnerabilities of storytelling, they have means – discursive and methodological – to allay disbelief. No reader need begin an ethnography by suspending disbelief, although he or she may come to that position if overly exceptional cases are consistently presented, unmoored from some mundane everyday reality. However, although boring, the mundane is believable: the more exceptional cases become, the more incredible, the less able they are to sustain the belief of the reader, although, in their moment, they may make for compelling reading.

The representations of cases can be moulded away from their empirical basis, but this practice has its limits and, at least in the cases I present here, that limit is history. These limits are the limits of realism though, and are self-imposed: I could wander further in my representations if I were willing to wander deeper into the rhetorical. For me, the aim in my presentation of these cases of disorderly sleep – both here and in my work more generally – is to think through the contortions institutions produce in the human body: what people have to do to align themselves with the expectations of normal everyday life in the USA through the manipulation of their bodies to meet the demands of the institutions with which they interact. So, although I might trade sleep disorders for some other condition, ultimately I must be able to still reach the same conclusions. If that substitution would render the cases more compelling, it might be worth the potential disbelief readers would bring to the text. But, it might mean this text would be something other than ethnographic, and more appropriately thought of as fiction, pure and simple.

The line between fiction and ethnography, however, is a fine one, and when it is muddled, it upsets not simply the text at hand, but generic conventions of documentary representations across disciplines, not solely related to writing.

Nearly thirty years after the critiques of representation that rocked the ethnographic social sciences and anthropology especially, the arts of ethnographic writing no longer seem so explicitly controversial. That this is so may have less to do with the generic conventions of ethnographic writing than it does with the changing expectations of social science readers. Or it may be a balance of the two, relying on changes in writing and reading practices. Writers and readers have become accustomed to particular kinds and degrees of disclosure on the part of ethnographic writers and their interlocutors: too much unsettles a text by making it appear too subjective, too little renders a text inert by inferring a level of objectivity that is not credible. This state of affairs might not be the best for ethnographic writing as it may index growing apathy with regard to ethnographic writing, for writers and readers both. It may index the strictures of the market on social science writing, where more experimental forms of presentation are seen as a market risk rather than a valuable experiment. Whatever the reasons for the decrease of experimental ethnographic writing, ethnographers have at their disposal means to expand the limits of ethnographic writing by experimenting with how and what they disclose, that is, their methods, their knowledge, their interlocutors and the worlds they hope to construct through their ethnographic texts.

Ethnography is fundamentally an ethical practice. This ethical relationship is generally assumed to be between the ethnographer and his or her interlocutors, as the ethnographer works to both be faithful to the experiences of his or her subjects and also works to protect their identities and material, everyday situations. But, given that ethnographic writing now balances the demands of disclosure on the part of writers as well as interlocutors, the ethical relationship embedded in every ethnographic text is fundamentally between writer and reader. One last disclosure, by way of example: during the same period in which I interviewed Ryan and other disordered sleepers, I interviewed a man named Ken. I met Ken through Talk About Sleep (www.talkaboutsleep.com), an internet site dedicated to sleep-related support for individuals and their families. Ken was a relatively active member of the community, posting regularly and often responding to other people's posts with his own experiences navigating his anxiety-related insomnia and obstructive sleep apnea. I eventually asked if he would be agreeable to a telephone interview, and we set up a time. Although my life history interviews with disordered sleepers often stretched past an hour and a half, as we discussed their family, school, work, recreational and medical histories, my interview with Ken was a terse eleven minutes. He would answer my questions with one- or two-word answers and never elaborated his answers when prompted. At the end of the interview – which I struggled

to stretch out – I felt embarrassed. It was my first real interview failure. But it was not my last. Of the interviews I conducted with disordered sleepers, about 10% of them were equally awkward.

Why have I waited so long to make this disclosure, one that is fundamental to my experience as a researcher and has bearing on the presentation of my data? That social scientists do not regularly admit their failures troubles the veracity of social science claims. If our science is built only upon positive evidence, that is, only built upon success, means that a world of seemingly unasked questions remains, despite answers maybe already existing. That we can choose to admit our failures or not highlights the ethical burden inherent in ethnographic writing; we are always choosing whether to tell the whole truth or only part of it, whatever generic conventions we choose to deploy. Full disclosure may never be possible as a practice of ethnographic writing, but until we come to terms with the powers and limits of disclosure in our writing, we will have yet to reckon with the reflective critiques of the 1980s that challenged – and seemingly continue to challenge – dominant forms of ethnographic representation. Which is all to say: have I disclosed enough?

Note

- 1 I am indebted here to Christopher Priest's novel *The Affirmation* (Priest 1996 [1981]), in which the protagonist sets about writing his autobiography and finds the factual presentation of his life to lack truth; only by rendering it increasingly fantastic is he able to get to the truth of his experiences. By the end of the novel, it is unclear whether his initial presentation of reality is factual or if that was the fiction he created.