

After illness, under diagnosis

Negotiating uncertainty and enacting care

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Abstract

A vast portion of the world's population live with ill health following acute infection or disease and its emergency management. This reflects the increased capacity of technological innovations and pharmaceuticals to interrupt decline or complications, even when cure is unlikely. The authors in this Special Section illustrate how, in different localities, people live with risk for themselves or their offspring; with non-communicable, degenerative, autoimmune, and congenital conditions; with the after-effects of diagnostic procedures and surgical interventions; and with continued treatment and surveillance. We attend to the value of conceptualising this as 'living under' diagnosis or description. We illustrate how diagnostic labels overdetermine subsequent embodied states of being, structuring interactions and social relations with family, friends, and health professionals. Living under diagnosis, we argue, impacts on self-care, care for and by others, everyday lives, and anticipations of the future.

Keywords

chronicity, diagnosis, biomedical interventions, medicalisation, prognosis

We sometimes speak and write of illness as if it were linear, divided into blocks of time – sickness, disease, diagnosis, treatment, cure, remission, recurrence – discrete events, clear demarcations, rather than murky spillage from one state to another. Anthropological as well as epidemiological definitions of sickness, disease, and diagnosis turn on these distinctions;

clinical consultations are framed by them. Yet, from personal and ethnographic experience, we know that this is an analytic artefact. How we live with ill health involves considerable convolution during clinical encounters and over time. In general, mild health problems and acute conditions – a mild respiratory tract infection, a contusion, a simple fracture, various bacterial infections – are experienced by the sufferer as following a predictable pathway of symptoms, diagnosis (lay or medical), and resolution. In contrast, bodily conditions and ailments that stretch out over time bring with their diagnosis the need for continuous action: monitoring, review, diagnostic refinement, individual and interpersonal challenges of therapy, likely complications, comorbidities, decline, and, sometimes, the presage of and action in response to return. Contested conditions, when definitive diagnosis, treatment and cure are elusive and when the management of symptoms is a matter of trial and error, are even trickier.

The narratives of the passage of ill health or ability often fit poorly with how they are experienced by individuals, how different physical, psychological, and social factors feed into perceptions of states of (ill) health, how diagnoses are constructed, and how these shape people's lives thereafter. In this Special Section, we focus on bodily disorder and difference, diagnostic labelling and treatments, and the responses, interactions, contexts, and technologies that shape conditions over time. Hence the title: *After illness, under diagnosis*. We attend to the ways in which perceptions of illness and deviations from normality, by sufferers/patients and by clinicians, are both prior to diagnostic processes and naming, and subsequent to diagnostic technologies, classification systems, and labels. Social and economic circumstances, the conditions of everyday life, and understandings of illness map out life after, or under, diagnosis. As the various authors illustrate, the personal, technological, and structural factors that shape diagnosis and its impact are rarely simple.

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In her account of bipolar disorder, Emily Martin (2007) writes of 'living under' diagnosis or description. This phraseology provokes us to think of and write about other physical and mental health conditions, understanding that the term acknowledges how a diagnostic label is applied at a moment in time, and how thereafter it impacts on personal living and social interactions, structuring relations with various health professionals and with family and friends. The idea of living under diagnosis acknowledges: the role of the label in determining symptom management, monitoring and measurement; its power in directing action and behaviour, even if there are conflicting or varied symptoms; its accuracy for any particular person; and the possibility and effect of its reversion. As a result of a set of symptoms, a diagnosis is possible; as a result of a diagnosis, the symptoms (of a disease or condition) have a social as well as biological life.

This social life is produced by multiple actors and their various interactions. Such interactions include the relationships of individuals living under a label: with others; through post-diagnosis technologies and materials; emerging from behavioural, 'lifestyle', and pharmaceutical prescriptions of managing symptoms that might be resolved, controlled, or persist; through the biometrics that are produced as evidence of disease containment or progression. 'Living under' emphasises that illness, once named, is an assemblage. It flags that any diagnosed condition is pre-scripted, defining the technologies of management and engineering how life is lived. The diagnosis reshapes the self and self-care. It foreshadows the development of the condition and has prognostic capacity – it foretells subjectively what might be, and the conditionalities of heading off certain outcomes. All of these factors vary significantly in relation to personal, technical, and state resources, and diagnosis becomes possible and conditions come into being only as methods and measurements bring signs and symptoms together in ways that cohere to produce a given label.

For any and all chronic or congenital conditions, diagnosis provides a framework for interpreting further signs and symptoms, at times over-determining the meaning of embodied shifts in states of being. Diagnosis provides an entry point to the heightened awareness of and concern to prevent complications, new abnormal functions, comorbidities, and unrelated infections for non-communicable long-term or life-long conditions, and sets out known risk factors that might lead to exacerbation. This is evident in that ways in which diabetes, heart disease, and various other physical health problems are managed, as Carolyn Smith-Morris discusses in this issue. It is evident also in the care of people with degenerative diseases and other conditions that might first present acutely, but continue to unfold in unpredictable ways, shaped by social and physiological chronicities (Manderson and Smith-Morris 2010; Manderson and Warren 2016).

Cancers are a particular example of this uneven temporality, and biomedical interventions do not change the need to live with and under diagnosis. Rather, diagnosis may sustain, even if it reshapes, patienthood. The majority of people who have cancer surgery, for instance, live with an aftermath. Phased from acute to chronic, and perhaps back to acute to chronic again (in the case of recurrence), an affected person, family, and physicians engage with annual screening and monitoring, ultrasounds, X-rays, biopsies, continuing treatment and adjuvant therapy, scarring and dysfunction, and more (Jain 2007; Manderson 2011). The initial diagnosis and the drama tied to cancers live on through treatment routes and prognoses, so that a person might always actively live under diagnosis. The self is subsumed by the diagnosis; he or she becomes a 'cancer survivor' in a broad imaginary and through their personal social networks and interactions.

People who have bariatric surgery or transplant surgery likewise necessarily restructure their lives to live with a new chronic condition, shaped by the chronicities of its management and other health problems and everyday social and economic circumstances (Manderson 2011; Manderson and Warren 2016; Heinemann, this issue). For example, over the past century, depending on social and cultural setting, obesity has shifted from symbolising plenitude to signalling bad eating habits or metabolic dysfunction, to a risk factor for disease, and then to a disease itself. Increasingly, obesity is bundled together with diabetes and heart disease as metabolic syndrome, a known risk factor for further complications, from neuropathy and blindness to end-stage kidney disease and depression. The challenges that many people face in shedding weight through diet and exercise lead them to bariatric surgery (Bell et al. 2019). But the success of the procedure requires dramatic changes in food habits and meals, and a reworking of how to participate in meals, transforming sociality and care in consequence. They must necessarily adhere to rigid prescriptions of diet, nutrition, and eating to avoid the slow undoing of their surgical gains.

Neurological degenerative conditions such as multiple sclerosis, Parkinson's disease, and Huntington's disease (Flaherty, Preloran, and Browner 2014) likewise always define the person 'under diagnosis'; the possibility of remission, recurrence, or deterioration gives diagnosis its particular edge. And, in a particularly direct manner, people with auto-immune conditions (such as lupus and multiple sclerosis), auto-immune mediated disorders and syndromes (such as gluten intolerance, lactose intolerance, and allergies of various kinds), and compromised immunity after surgery (such as splenectomy and with transplants) always live under and with diagnosis. Diagnosis governs everyday activities. The most quotidian decisions – what and when to eat, and what kinds of medications to take, when and in what quantities – become careful calibrations to minimise reaction, discomfort, infection, risk of severe morbidity, or possible death. Clinicians 'take on' the responsibility of over-viewing their patients and their adherence to such prescriptions: living under diagnosis almost always involves living under clinical as well as social surveillance and active care.

How this becomes an opportunity, for pharmaceutical companies for instance, is at the core of Joseph Dumit's work, *Drugs for Life* (2012). Disease may be imperceptible, but as Dumit illustrates, there is growing clinical emphasis on predictive 'virtual pathologies' – the diagnostic risk signs or probability linked to a contemporary predictive moment and contemporary biomedical understandings of pathogenesis (Adams, Murphy, and Clarke 2009; Greene 2007; Warren and Addison, this issue; Heinemann, this issue). Signs and possible symptoms – a higher than pre-defined 'normal' or 'desirable' blood cholesterol level, for instance, or a lower than 'normal' or 'desirable' haemoglobin level – are identified as pre-diagnostic of chronic conditions that might develop downstream. To head off such conditions, medications – statins, anticoagulants, antihypertensives, and antiarrhythmic, anti-hyperglycaemic and antioxidant drugs – are prescribed (Greene 2007). Being on medication involves a continuing

relationship with the treating physician, tasked to monitor biomarkers or check for the emergence of new signs, so seeking for indications of dysfunctions while assessing the continuing effectiveness of the medication prescribed. Thus, patienthood is reinforced and reiterated by living under diagnosis; it colonises the individual (Smith-Morris, this issue). Minimally, the physician is granted – or assumes – authority after diagnosis over a patient's access to medication and other services, so managing not only the diagnosis but also its attendant risks.

In this Special Section, we include Position Pieces and research articles that take diagnosis as a starting point and as a continuing experience. People may be counselled to seek diagnosis on their own or another's behalf for the resolve it might bring (as in the case of prenatal diagnosis, see Sargent, this issue; also Flaherty, Preloran, and Browner 2014). By taking on diagnosis, patients are colonised by biomedicine (Smith-Morris). Such colonisation might be resisted through alternative modalities, but as biomedicine has travelled and comes to dominate medical care, so the technologies of diagnosis, including medicine's simple and affordable accoutrements, legitimise the diagnostic work of alternative practitioners. Whatever the modality, diagnosis helps people make sense of the incommensurability of persistent poor health or impairment (Rubinstein and Sakikabara). It can identify steps to reverse it surgically, and for those who always live under diagnosis, as occurs with transplants, it helps sufferers and others live with symptom fickleness and uncertainty, along with other shifts in health and capacity (Heinemann). And diagnosis offers the possibility of cure, with each advance in biomedicine, through new discoveries, techniques, and approaches (Warren and Addison; Hammad Mrig). I briefly summarise the contributions of these authors below.

Mimicking the chronologies of life and the transit from signs to diagnosis to treatment, I begin with Christine Sargent's article – where there are no signs or symptoms of disorder, nor yet the person bearing them. Drawing on ethnography conducted in Amman, Jordan, Sargent is concerned with prenatal screening and diagnostics, and the tensions that this technology inserts into the lives of pregnant women. Prenatal screening and diagnostics are, Sargent argues, 'technologies of subjunctivity' in relation to the foetus, but for the women with whom she has worked, conditionality was associated with having, or not having, the diagnostic procedure, rather than acting upon its results. In this context, women drew on the availability of prenatal diagnostic technology, its capacity to identify Down syndrome, and the immoral potential of elective abortion, to position themselves as good and righteous. Women used 'subjunctivising tactics' to work through the moral dilemmas that testing might present, through its capacity to define a state that could not be changed and/or that enabled change in a manner that was, to them, morally untenable. Ultimately, women regarded the practice of

prenatal diagnosis as reifying ideas of normalcy, legitimising the exclusion of those who deviated from this. By extension, support of prenatal diagnosis was equivalent to rejecting their own children with Down syndrome.

In this context, affect and emotion play a major role. While Sargent's respondents rejected the idea of diagnosis, in some cases people are eager for it as a way of making sense of the limits they experience on their capacity to function as 'normal'. For many conditions too, there is considerable subjectivity in what count as symptoms and what constitutes a condition, when a patient's account of poor health or fatigue is no longer dismissed as an indicator of some other mental or social problem. In such contexts, failure to receive a diagnosis may be much harder than its confirmation; clinical medicine has the capacity to determine life outcomes by validating an everyday life. Diagnosis establishes order over signs and symptoms, and so enables the introduction of strategies to overcome them, whether medical, surgical, or behavioural, as in the case of various conditions linked to 'lifestyle'. With diagnosis, the patient is offered the possibility of recovery – or, at least, a knowable future.

But, as Carolyn Smith-Morris illustrates, diagnosis transforms patient experience into medical knowledge. Through this, she explains, clinicians aim to co-opt and re-orient patients' self-knowledge into a hybrid understanding that will inspire appropriate patient behaviour. Drawing an analogy between colonialism and medicine as ideological systems through which control is exercised, Smith-Morris extends Homi Bhabha's (1994) ideas of hybridity and difference to analyse self-perception and self-diagnosis, and the self-colonisation that precedes any clinic encounter. In doing so, she draws on narratives from patients with end-stage renal disease, their diagnostic encounters, and their subsequent shifts to comply with clinical interventions and prescriptions. Building on her earlier work (Smith-Morris 2015), she sees diagnosis as both an expression and a vehicle of medical authority and power – a rubric that clinicians use to declare a person ill or not.

Not all diagnoses fit with biomedical nosology, however. Ellen Rubinstein and Rae Sakikahara provide an example of a diagnosis that emerged in Japan, describing the social withdrawal of young people while avoiding a psychiatric diagnosis such as schizophrenia. In this context, 'living under' the condition of *hikikomori* helped to make sense of the experiences of social withdrawal for those who suffered, and for family members who took on the responsibility for their child's health, struggled to make sense of the condition, and debated whether or not to seek psychiatric care. Without the stigma of a psychiatric condition, hikikomori also enabled parents to meet in support groups. While it has been linked to family dysfunction as well as individual psychopathology, it has also been explained in relation to social expectations on young people and the lack of employment opportunities available to them to meet these. While living under a psychiatric diagnosis medicalises the condition, hikikomori allows young people to access social and vocational programmes; as it is a lay condition, not a mental illness, young

people escape disabling diagnosis through this label. Rubinstein and Sakikahara illustrate that sufferers living under the diagnosis of hikikomori are able to avoid the medicalisation and colonising effects of a psychiatric diagnosis.

In writing of kidney transplants, Laura Heinemann provides an example of how a life-changing procedure necessarily perpetuates patienthood. The constricting endless routines of dialysis are replaced by care for the grafted kidney, most directly by the need to adhere to immunosuppressant medication to prevent rejection, other medication to address adverse effects of the long-term use of immunosuppressants and to avoid infection, regular visits to clinicians, and pathology tests and monitoring for signs of rejection or poor function. In both bariatric surgery and transplant surgery, people learn new techniques of self-care and forge new ways of relating to others, as they continue to live under diagnosis.

The final two Position Pieces bring us to questions of cure, contrasting with the implicit premise of the absence of cure in the examples above. Narelle Warren and Courtney Addison begin by considering precision oncology, which moves our understanding of cancer from site or organ to the treatment of tumour mutations across diagnostic type. Next, they focus on neurodegenerative diseases such as Alzheimer's disease, Parkinson's disease, and motor neuron disease, and the potentiality for their cure, even while diagnosis is problematic (for instance, Alzheimer's disease can only be diagnosed definitively through autopsy). In the last Position Piece, Emily Hammad Mrig takes the case of breast cancer, and considers how the risk of occurrence might be anticipated, so provoking moral dilemmas similar to those that Christine Sargent introduced in her article on prenatal diagnosis. Does it help to know that there is a chance, a risk, based on genetic work-up, of a given condition? If so, what action might be taken: the initiation of or increased screening and testing; the decision not to reproduce; pre-emptive medication; prophylactic surgery (in Heinemann's case), or abortion (as in Sargent's)? Although 'cure' is often elusive, the knowledge of vulnerability to disease places on patients a moral obligation to act. Hence genetic identification acts as a pre-diagnostic to avoid, through consequent intervention, the development of illness and disease.

Two issues stand out in this regard. Firstly, as Warren and Addison illustrate, genetic testing indicates risk but not actuality; prophylactic action does not head off all conditions associated with a designated gene, and action in one domain does not interrupt the possibility of other health conditions that are equally as troubling, disrupting, or disturbing. Further, through calculating the possibility of disease, the individual and genetic family members are now defined as not-yet-ill, as pre-patients, stimulating actions for both prevention and cure, even in the absence of the condition. As these authors note, the idea of cure 'crowds out other possibilities of care'. Secondly, Hammad Mrig considers the targeted interventions that are contingent on genetic testing, for example, by classifying the tumour to determine immediate

and longer-term treatments and follow-up. As Hammad Mrig observes, the ability to choose a treatment pathway is often, although not only, determined by health insurance plan. But further, access to the technology of genetic testing, the information such technology produces, and the opportunities to act on such knowledge, are bundled together with relative wealth at both individual and national levels. Likewise, the opportunities to take advantage of precision diagnostic tests – and so, following diagnosis, to opt for or against specific surgeries, gene and cell therapies, or chemotherapy – are shaped by what is possible technically, ethically, and financially within and between country settings. Access, that is, is deeply uneven.

After illness, under diagnosis captures the various pathways of signs and symptoms, tests and measurements, diagnostic proclamations, and the experiences of living thereafter with a particular condition, or with the repercussions that follow curative action. How diagnosis is pre-scripted, dominating everyday life and shaping interactions with others, over-determines shifts in health status. The diagnosis, we have argued, reshapes the self, how life is lived, and what might come to be.

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