



Experts and ‘knowledge that counts’: A study into the world of brain cancer diagnosis

Sky Gross*

The Department of Sociology and Anthropology, The Hebrew University of Jerusalem, Israel

ARTICLE INFO

Article history:

Available online 12 October 2009

Keywords:

Israel
Expertise
Epistemology
Diagnosis
Hospital
Fieldwork
Authoritativeness
Brain cancer clinic

ABSTRACT

This paper provides a close, *in situ* look into the life of a neuro-oncology (brain cancer) clinic of a large hospital in Israel, based on a six-month participant observation. It points to the many challenges involved in the solidification of brain tumour diagnoses by different experts, and presents these epistemological and practical complexities as they uncover in daily routine. The paper’s task is two-fold: first, to underline the technological and epistemological grounds of ‘expertise’ in the medicoscientific practice of diagnosis, and their roles in the assertion of expert authoritativeness; and second, to provide analytical tools to approach the complexity of diagnostic processes, the potential frictions it may create, and the related mechanisms of resolution. These mechanisms include *Hierarchisation*: ranking the relative validity and reliability of the different sources of information, eventually prioritising reports from more authoritative expertises (e.g. imaging reports would be considered more reliable than patients’ accounts); *Sequencing*: relying upon the temporal dimension, and defining the discrepancy *itself* as a diagnostic sign (e.g. the degradation or amelioration of the disease); *Negotiation*: adjusting diagnoses *via* a preliminary exchange between experts and a consequent “fine tuning” of the reports (e.g. radiologists being aware of clinical evaluations before finalising their reports); *Peripheralising*: turning to other expertises to “explain away” symptoms that do not fit with a well established initial diagnosis (e.g. asserting that a symptom’s source was orthopaedic rather than neurological); and *pragmatism*: using information only as far as it provided sufficient grounds for treatment decisions, leaving ambiguities unresolved. These five mechanisms are presented here in the context of the daily work of the clinic.

© 2009 Elsevier Ltd. All rights reserved.

The majority of medical texts represent brain tumours as involving fairly clear-cut entities and categories of entities, amenable to “discovery” through different practices. A closer look into the life of a neuro-oncology clinic proves, however, that the solidification of neuro-oncological objects is less than straightforward, in both epistemological and practical terms. This study sought to provide an *in situ* understanding of the ways in which diagnoses are handled in medical experts’ daily routine *via* an immersion into the everyday practice of a wide range of experts. The aim of this paper is two-fold: first, to underline the technological and epistemological grounds of ‘expertise’ in the medicoscientific practice of diagnosis, and their roles in the assertion of expert authoritativeness; and second, to propose analytical tools to approach the complexity of diagnostic processes, the potential frictions they may create, and their mechanisms of resolution.

As suggested by such scholars such as Philip Brown (1990, 2008) and Annemarie Jutel (2009), works on the social and cultural

aspects of diagnosis require framing within the field of a ‘sociology of diagnosis’. Following this literature, this paper will attempt to provide potentially useful definitions of epistemological issues underlying the practice of diagnosis.

Methodology

Over recent decades, a new approach to the study of medicoscientific work has arisen, seeking closer attention to the everyday practices of ‘making science’ (e.g. Latour & Woolgar, 1986; Lynch, 1988; Pickering, 1992; Rabinow, 1996). Drawing on this now considerable body of research, this paper will present an ethnographic study which allowed for a sustained *in situ* observation of the daily micropolitics of diagnostic practice.

In the first half of 2006, I followed the work of members of a neuro-oncology outpatient clinic situated in a large hospital in Israel. The team consisted of four neuro-oncologists (henceforth NROs), a head nurse, a social worker, and a neuropsychologist. The NROs were observed during routine consultations; in rounds in the inpatient ward; and in the course of three weekly professional

* Tel.: +972 2 6437381.

E-mail address: crosss@mssc.huji.ac.il

conferences: one internal conference, one with the radiology experts, and one with the neurosurgical team. I spent some twenty hours a week at the clinic, where I gathered extensive field notes (simultaneously translated and composed in English) along with both formal interviews and casual exchanges with staff members, patients, and close-ones. Forming a small share of the data collected, formal interviews – 13 overall, 4 with NROs, 2 with family members, and 7 with 5 different patients – were later transcribed *verbatim*. The field data was then analysed around themes that seemed to recur, namely, the dynamics of the exchange of information among different team members and patients. In line with “grounded theory” methodological approaches, the analytical scheme was built and refined in constant conjunction with the empirical data, and the data itself came to be read with this scheme in mind.

Being, in a way, the physician’s home ground, the hospital constitutes a crucial setting for understanding the world of medical experts (e.g. Anspach, 1987; van der Geest & Finkler, 2004; Mizrahi, Shual, & Gross, 2005). The lengthy work of negotiation and clarification, namely with the head of the clinic, led to the gradual gaining of the staff’s confidence. Finally, formal permission from the hospital’s Helsinki ethics committee allowed me to begin my work. By the end of this process, I was accorded access to the innermost stages of the clinic. Anonymity is ensured by the use of pseudonyms throughout, again, for both patients and staff. Considering the level of intimacy I developed with the patients, I felt more comfortable using first names as pseudonyms, while referring to staff members in a manner that would reflect their professional roles, rather than on *ad-hominem* aspects of their work (i.e. Dr. X.).

In view of the intricate nature of the field of neuro-oncology and the complex terminology used in interactions, I spent months prior to my insertion in the field studying related medical texts. In fact, it seems one can hardly communicate the “real life” work of the professionals without referring, however critically, to these schemes. I had to repeatedly make clear to patients that I retained neither a medical nor counselling role in the clinic, especially as I wore, as requested by the staff, the traditional white robe. However, as the proper ethical directives were followed, and as cooperation was ensured, this did not seem to eventually form any significant obstacle.

At the clinic: the diagnostic process

According to textbook medical knowledge, a brain tumour arises out of the proliferation and multiplication of a single cell, which, for reasons little understood, goes through molecular mutation. At the histological level, these will reproduce, create their own blood supply, and eventually become numerous enough to apply pressure on adjacent nervous tissues. The tumour presents itself through a neurological realm of signs and symptoms, which may include epileptic seizures, total or partial paralysis, speech malformations, visual disturbances, loss of sensation in the limbs or, in some cases, personality changes. Reporting diagnostic information such as biopsy and MRI studies, along with clinical impressions, allows NRO to determine the locality of the tumour, its size, the types of cells involved, and its degree of malignancy.

At the clinic, this process begins with the first encounter with the patient. There is a fairly ritualistic intake of new patients, where the NRO assesses previous findings, gathers a clinical history, and performs a physical examination. If judged necessary, immediate intervention is considered, *albeit* only once options are discussed in conjunction with other experts, such as radiologists and neurosurgeons, and, if applicable (*viz.* the tumour is metastatic), with the primary oncologist. In either case, treatment options (including, usually in this order, neurosurgery, chemotherapy, radiotherapy,

clinical trials, and palliative care) are deliberated among a relatively large array of biomedical professionals.

Routine assessments of cases are typically performed in the course of three weekly conferences. First there is the NROs’ staff meeting where each physician is expected to present the files of the patients he/she has seen throughout the week, with his/her colleagues offering their opinions and evaluations. The second meeting proceeds at the MRI unit, where the radiologists go through recent imaging tests while the NROs provide clinical information on their patients. The former then report their impressions, first orally to the staff (“*things look bad, tut tut tut*”), and later in writing (“*a slight compression of midbrain structures was observed*”). The third meeting, the ‘tumour board’ –which includes the NROs, neurosurgeons, and radiotherapists– seeks a collective appraisal of the applicability of different surgical or radiotherapeutic protocols (“treatment algorithms”). Its place within the diagnostic complex is limited, and the approach is largely task-oriented. The only common participants in these three sessions are the NROs, a fact that reinforces their centrality in the diagnostic process. Indeed, as the integration of reports into a compiling diagnosis requires the adoption of a common way to ‘speak of’ the disease, the participants (*i.e.* the reporting experts) are expected to conflate their way of ‘speaking of’ the disease to the NROs, thus placing the latter in a position of significant power (Mol, 2002).

The interaction between professionals is critical both before and after initial diagnosis. Patients attend the clinic up to once a week while under a radiotherapeutic regime, and once a month when under chemotherapy – typically referred to imaging tests every few weeks. In fact, for a brain cancer patient, diagnosis is literally a lifelong process; For the NRO, each diagnostic function defines a point on a temporal line which presumably depicts a logical evolution of the disease, usually towards a worsening in all diagnostic values. The “case” thus remains in a certain state of fluidity, where each re-assessment demands further exchanges of “reports” through the web of expertise.

Medicoscientific diagnosis

With the proliferation of diagnostic technologies, the practice of medicine has become increasingly dependent on expert medicoscientific observation, adding to the intricacy of medical work (Dew, 2001; Howell, 1995). This is accompanied by the need for a constant reshaping of the definition and conceptualisation of disease, most prominently in fields where diagnosis remains complex and critical (Casper & Koenig, 1996; Clark & Mishler, 1992; Reiser, 1978).

Facing sets of signs and symptoms, physicians are expected to “reveal” the one underlying element: ‘the Disease’. This quest aims at a reconciliation of accumulated diagnostic data (e.g. clinical examinations, blood test results) and the preconceived nosological scheme of knowledge regarding diseases’ characteristics, expected course, and likelihood to respond to certain treatments (Foucault, 1963; Lynch, 1988; Moreira, 2000). This integration of pathology and nosology requires a ramified process of creating, changing, communicating, and alternating definitions of “the Disease” as one epistemological object (e.g. Berg & Mol, 1998; Mol, 2002; Moreira, 2004). In many biomedical settings, this process involves a multiplicity of experts: within each expertise, diagnostic elements are observed, explained, assigned attributes and boundaries within its specific “styles of reasoning” entrenched within formal and tacit knowledge (e.g. Bos, 2004; Good, 1994). As Polanyi (1998) and others (e.g. Collins, 2001; Hacking, 1982) have shown, expert conceptualisation of pathologies is further mediated by technology (e.g. an MRI machine), a form of attention (e.g. the analysis of the spatial characteristics of a tumour) and a hermeneutic agent

Download English Version:

<https://daneshyari.com/en/article/953546>

Download Persian Version:

<https://daneshyari.com/article/953546>

[Daneshyari.com](https://daneshyari.com)