

“I have become a microscope for my own body”: local biologies and the embodiment of biomedical knowledge¹



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Abstract This paper explores the way those commonly described as “lay persons”, “the public” or “patients” appropriate biomedical and biological knowledge and make it part of their repertoires of experience, including embodied experience, as well as the specific apparatuses or *dispositifs* associated with health promotion or education. The paper draws on an

Resumo Neste artigo, explora-se a forma como aqueles que são vulgarmente designados de “leigos”, “públicos” ou “pacientes” se apropriam do conhecimento biomédico e biológico e o convertem em parte dos seus reportórios de experiências, incluindo as experiências incorporadas, assim como dispositivos específicos associados à promoção ou educação em saúde. O artigo baseia-se numa inicia-

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experimental initiative in health promotion in Brazil. This initiative raises intriguing challenges to current approaches to what counts as knowledge and how it is associated with the empowerment of citizens in relation to health.

Key words Local biologies; experience; embodied knowledge; health promotion; Brazil.

1.

Over the last two decades, and in the wake of Michel Foucault's work, of feminist scholarship, criticism of medicine, biology, and of earlier work in medical anthropology, a considerable body of research has emerged on the entanglements of biology, power, sociality, citizenship, biomedicine, subjectivity and body politics. It would be futile to attempt to provide here even a cursory overview of the main directions or contributions of this line of work. I shall rather focus on a topic which has been recently taken up by Margaret Lock and Vinh-Kim Nguyen in their landmark *An Anthropology of Biomedicine* (2010). I am referring to what they describe as local biologies, a major outcome of the global outreach and growing influence of biomedicine as a key constitutive aspect of contemporary societies.

tiva experimental levada a cabo no Brasil no domínio da promoção de saúde. Esta iniciativa suscita alguns desafios interessantes às definições do que conta como conhecimento e ao modo como este está associado à capacitação dos cidadãos no domínio da saúde.

Palavras-chave Biologias locais; experiência; conhecimento incorporado; promoção da saúde; Brasil.

Rather than a straightforward definition of local biologies, Lock and Nguyen offer an extended commentary on the relevance of that concept – initially coined by Lock “to account for differences in symptom reporting at menopause” (Lock and Nguyen, 2010: 90) – for dealing with the ways “the embodied experience of physical sensations, including those of wellbeing, illness, disease, and so on, are informed in part by the physical body, itself contingent upon evolutionary, environmental, historical, cultural, medically induced, and individual variables. Embodied experience is also informed, of course, by language, culturally informed knowledge and expectations, social context, and so on” (Lock and Nguyen, 2010: 90).

The notion that experience is embodied has been around at least since Merleau-Ponty's approach to being as bodily engagement with the world. Later approaches have looked for exten-

sions of this notion towards a cognitive conception, which tended to identify the embodiment of cognition with the activity of the brain and the central nervous system. More recent developments, however, have challenged brain-centered approaches through extended inquiries into what may be described, in shorthand, distributed modes of embodiment (Wilson, 2004). I have drawn heavily on this literature, sometimes summed up under the headings of “new materialism” or “material feminism”¹, to follow through a key point made by Lock and Nguyen: the idea that embodied experience is “informed”, not only by the physical body – as a biological entity –, but also by what is usually described as the social and the cultural, including “culturally informed knowledge”. The point may sound like one more reminder of a concern at the core of the endless debates on nature and nurture, but it still raises a formidable challenge to inquiries on how local biologies emerge and what it means to say that they are “informed” by the range of processes/entities listed by Lock and Nguyen. The word “informed” brings to mind associations with the contested notion of information as a shorthand for the diverse and complex forms of intra-action in the world – i.e., modes of “making” the world through the “cuts” which divide agencies and objects, including the nature/culture or bi-

ology/society cut (Barad, 2007). The role of formalized procedures/apparatuses for producing knowledge – such as science or other technical modes of knowing – has to be brought back into the discussion of how these cuts – such as that between disease and health, or body and environment, or knowledge and ignorance – are established, enforced or challenged.

My specific interest in this paper is to offer a first inroad into the way local biologies are “informed” by modes of engagement with biomedical and biological knowledge by those often described as “lay persons”, “the public” or “patients” – as opposed to researchers, clinicians and other actors associated with the production and technical/professional deployment of those forms of knowledge. How do these actors appropriate biomedical and biological knowledge? How do they make it part of their repertoires of experience, including embodied experience? How do they deploy it in everyday or problematic situations? What are the specific apparatuses or *dispositifs* associated with health promotion or education which allow the appropriation of biomedical and biological knowledge? In the following sections, I shall provide a preliminary discussion of the topic by drawing on my reading of, and engagement with, an experiment in health promotion in a specific context, that of Brazil, which is an instance of setting up an apparatus or *dispositif* allowing the production/sharing of knowledge on disease, health, the body

¹ For a review of some recent significant contributions, see Hird (2009).

and environment. In the closing section, I will suggest how this experiment raises some interesting challenges to current approaches to what counts as knowledge and how it is associated with the empowerment of citizens in relation to health.

2.

In Brazil, the project of a universal health care system, established in the late 1980s as a fulfilment of health as a “right of all and a duty of the state”, as stated in the 1988 Federal Constitution, rests upon a political and cognitive project known as Collective Health, which has a strong focus on social and environmental determinants of health and on health prevention². The project is crossed, however, by a persistent tension between the public health priorities associated with that focus and the need to engage with local biologies and body politics through a mobilization of the resources and approaches of biomedicine. It is in relation to health issues such as infectious diseases, its prevention and treatment - which was the original breeding ground for Brazilian medical science -, that this tension tends to surface more intensely. It will thus not be surprising that initiatives in health promotion, which tend to

rely on a strong focus on educational approaches, are fraught with this tension.

The case I shall be dealing with here is that of an experiment in the mutual engagement of health professionals and researchers, on the one hand, and groups of “non-specialists”, on the other, which intended to afford a space allowing for the collaborative production of knowledge on health in a way distinctive from more conventional forms of “health literacy”. The design of this initiative aims at allowing participants to work together with specialists to put to the test their experience and knowledge of health and disease in relation to the specific settings where they live and work, and to work through reconfigurations of that experience and knowledge. It offers an interesting instance of local biologies being enacted as the outcome of appropriations/embodiments of biomedical knowledge and of the iterative exposure of the latter to the experience-based knowledge of participants.

The initiative described below was launched in 2005 at IPEC/FIOCRUZ (Rio de Janeiro, Brazil). IPEC (Evandro Chagas Institute for Clinical Research) is one of the core units - actually, one of the earliest - of the Oswaldo Cruz Foundation (FIOCRUZ), a major public institution for health research and health promotion funded by the Brazilian Ministry of Health, one of the largest and most important institutions of its kind worldwide. IPEC is an institute

² For a detailed discussion of Collective Health, see Campos *et al.* (2007).

for clinical research and the provision of specialized care in the field of infectious and parasitic diseases in a dedicated hospital created about a century ago.

In 2007, and following requests by patients who were being offered care at IPEC, a team led by Claudia Vieira de Souza, an epidemiologist, established a “Study Group on the Epidemiology and Prevention of Infectious and Parasitic Diseases” as part of a research line on the epidemiological profile of the patients undergoing chemoprophylaxis for tuberculosis at the Institute. The success of this early experiment, and requests by other patients, their families and workers of the Institute and of FIOCRUZ, as well as the active engagement of the patient association of the Institute, opened the way to an autonomous project, which allowed the Group to be established as a regular initiative from 2008 onwards. A textbook was published, which is currently in its third edition (Souza, 2009). Participants receive a copy to serve as material for further initiatives of health promotion in their communities. Further editions of the Study Group were held from 2008 to 2011³.

In 2009, Claudia Vieira de Souza came to Coimbra and started work with the author on a postdoctoral project on the evaluation of the Study Group. This allowed a collaboration to get under way,

which was eventually formalized as part of a broader agreement between the University of Coimbra, CES and FIOCRUZ. The Study Group became a case study within a project, funded by the Portuguese Ministry of Science, Technology and Higher Education, on experiments in collaborative and community-based research related to health, life sciences and the environment, hosted by the Center for Social Studies of the University of Coimbra and involving as well two of the main research institutes in life and biomedical sciences in Portugal (IBMC and IPATIMUP, both located at the University of Porto). I have since made several visits to IPEC and participated in sessions of the 2010 edition of the Study Group.

3.

The objective of the Study Group was to “recover the concepts acquired in the course of formal teaching to facilitate the understanding of Infectious and Parasitic Diseases and consequently their prevention”. This was to be achieved “in a dialogical way, through the development of devices for the shared integration of the health team and the users” (Souza, 2009: 11). An informal assessment of the first edition of the Study Group emphasized its role in promoting both the “self-es-

³ On the Study Group, see Souza *et al.* (2008); Souza (2009); Neves *et al.* (2009).

team” of the participants and their capabilities for prevention.

On a first reading, the Study Group appears as one more instance of established approaches to health education, even if incorporating dialogical procedures, with the twofold aim of improving the knowledge and skills of participants for prevention and helping them to build self-confidence and self-esteem. I suggest, however, that the very design of the Study Group opened up, above all, a space where unexpected appropriations of biomedical/biological/epidemiological knowledge and the building of new forms of sociability became possible.

Each edition of the Study Group is organized as a series of 8 sessions, each dedicated to a specific theme, and bringing in specialists on each of the themes. Since the Group has, from its beginning, targeted poor or low-income participants, most of them current or former patients who have received specialized and sometimes long-term care at the Institute, participants are provided with vouchers for transportation and offered a light meal during the sessions. Following requests by participants in early editions, a decision was made to produce a book, with different chapters authored by the instructors in the course, which was offered to participants, who can then use it for further initiatives in their communities or neighbourhoods.

Some changes were introduced in the syllabus and organization of the study group over time, and the scope of its activities was broadened to include visits to museums, exhibitions, other medical or scientific institutions, and other locations of interest to the participants. But the original design of the sessions was maintained over its successive editions, even if a kind of iterative revision of the specific topics dealt with in each edition and of the actual workings of the sessions is recognizable.

The eight core themes which provide the contents for the sessions of each edition of the Study Group include the following:

- The basic unity of human beings
- Parasitic diseases: a matter of interaction with the environment?
- The systems of the human body
- The relevance of epidemiology: understanding, reflecting and acting
- Tuberculosis and AIDS
- Accidents with poisonous animals
- Medications
- A primer in the practice of preventing hospital infections

Sessions are held in a meeting room at the Institute. Presentations by “instructors” draw on a range of devices including slide shows, videos, but also the observation and manipulation of human

anatomic pieces borrowed from the anatomy department of a local university, of specimens of poisonous animals (snakes, spiders, scorpions...), work with small-scale models of different types of dwellings and environments for the identification of practices associated with vulnerability to infectious agents, parasites or poisonous animals and how to respond to them. Presentations, questions and discussions often merge into an extended dialogue, depending on the topic at hand. A large part of the time is devoted to engagement with materials and specimens, including their observation for size, shape and morphology, and their handling to feel for texture and resilience (for which latex gloves are provided). The observer stepping in for the first time will notice that there is a clear identification (through location and control of the allocation of voice) of who the instructors and the “students” are. The “cut” thus established, however, does not prevent the possibility of oral exchanges and (at certain moments during the session) of movement across the room.

At first sight, the study group would seem to be organized in a way which shares a lot with more conventional initiatives in health education: presentation of a topic by a specialist, who also acts as a facilitator of discussion and activities, followed by questions from the audience and replies from the presenter/facilitator. The second part of the session consists

of a hands-on engagement with materials of different kinds, including human anatomical pieces or specimens of poisonous animals. A closer look at the process, however, discloses some interesting differences.

The first has to do with the topics addressed. Take the session on “The systems of the human body”. Rather than just focusing on a description of cells, tissues, organs, systems or apparatuses and their functions, detailed attention is given to the links of these to certain pathological states, to how pathologies or lesions relate to the shape, size, texture or function of the organ. Bodily expressions of trouble, including pain, are brought back to the location, texture and function of the organs in question. If you are having a heart attack, why does it hurt elsewhere? The reading of symptoms is another popular topic: why is there no pain associated with some symptoms? How does this relate to anatomical and physiological features of the affected organ or system? Throughout the sessions, entanglements of the biological, the social and the environmental are questioned, as well as the implications of being provided with adequate health care in a timely way. Possible sources of confusion in diagnosis are highlighted, and the relationships as well as the tensions between vocabularies of experience and biomedical language are identified and discussed. Elaborations on these topics

incorporate and build on interpellations or questions by participants, taking as their starting point the way participants phrase their questions, inquiries or concerns in their own terms, and drawing on the vocabularies they are familiar with.

In a session on poisonous animals, a considerable amount of the time was devoted to the ecology of exposure to those animals, including all the conditions and features of human dwellings which generate vulnerability and exposure. As was made clear during the session, the kind of knowledge required for this kind of approach depends crucially on the contributions of participants to document and provide the elements necessary for the formulation of what Dewey (1991/1938) would call problematic situations.

4.

Still, the question remains of whether this type of initiative, despite its context- and experience-sensitive format, does not extend more conventional understandings of health education, health literacy and health promotion, with the aim, ultimately, of generating dispositions towards compliance with biomedical/public health knowledge. In other words, what kind of engagements with biomedical/public health knowledge

does this kind of *dispositif* allow? The answer is, of course, that there is room for different modes of engagement and for different ways of appropriating, circulating and putting to use the forms of knowledge arising from participation in the Group.

A common way of assessing how different non-specialist publics take up specialized (e.g., biomedical) knowledge consists of testing them for their capacity to give verbal accounts of what they have “learned”. An assumption underlying this mode of assessment is that “learning” requires both assimilating content and the “proper” way and vocabulary to state that content. Recent work by the pragmatist philosopher Richard Shusterman (2008) suggests a different way of understanding what it means to “inform” bodily experience, or, in other words, to “learn” with the body. Shusterman’s concept of somaesthetics is an attempt to capture this often neglected way of appropriating knowledge, including scientific knowledge.

To clarify this point, let us draw on a notion proposed by education researcher and activist Shannon Carter (2008). Against traditional notions of literacy advocating “minimalist” conceptions of what it means to be literate, Carter argues for an approach with a focus on the development of what she calls the “rhetorical dexterity” acquired by subjects. Within the health domain, this would

amount to a difference between a conventional health literacy based on a capacity to understand and comply with basic tenets of health promotion or biomedical indications, as the defining features of the “sanitary citizen” (Briggs and Mantini-Briggs, 2003), on the one hand, and a different kind of engagement with biomedical knowledge affording a kind of “cognitive dexterity”, which allows subjects to devise their own responses to recognizable threats to health or of setting up viable ways of protecting their health through specific bodily engagements with problematic situations. This includes a capacity to embody the knowledge of trouble or distress, through pain or other symptoms, opening up spaces for the empowerment of people which allows them to handle the “local biologies” constituted through the situated entanglements of biomedicine, society, environment and the politics of health and life.

The Study Group provides access to a range of sites within bodies and to processes relating human bodies, organisms, human actions, environments, health and social policies and violence, whose detection is beyond what we are able to capture with our “bare” senses. But it also offers a setting where symptoms as part of the embodied experience of participants may be related to processes and entities whose identification requires going through the devices

and concepts of biomedical, biological and epidemiological knowledge. How these relations are constructed would require the deployment of a full-fledged, collaborative research agenda. One participant offered a nice rendering of this intra-active dynamics of symptoms and access to knowledge of the “invisible”: “I have become a microscope for my own body”. What kind of experience does such a statement attempt to convey? And what conception of what counts as knowledge is implied by it?

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