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Living and coping with it: on the relevance of narratives of illness experience

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Introduction

Subjective accounts of illness enunciated as narratives constitute one topic of great importance in the sociology of health and medicine. These provide unique materials for exploring how subjects articulate their ways of making sense of illness, as well as to reflect on the explanatory models and salient prototypes (Kleinman, 1989) whilst building a link between their experiences and medical knowledge.

"Evaluating the State of Public Knowledge on Health and Health Information in Portugal" is a project funded within the Harvard Medical School – Portugal Program on Translational Research and Health Information, by the Portuguese Foundation for Science and Technology¹ (FCT). It also results from a partnership involving two research institutions, the Center for Social Studies of the University of Coimbra (CES) and the Institute for Molecular and Cell Biology – National Institute for Biomedical Engineering of the University of Porto (IBMC-INEB).

The purpose of this project is to explore new approaches to the experience of asthma and breast and lung cancer patients as they are articulated in narratives, through an adaptation of the McGill Illness Narrative Interview (MINI) schedule as its main tool.

The aim of this paper is therefore to present and discuss some preliminary findings drawn from interviews with asthma patients and breast and lung cancer conducted in Portugal. These indicate a considerable heterogeneity of each of the condition's paths, allowing simultaneously to confirm the MINI as an adequate tool to deal effectively with different illnesses, based on a substantial malleability.

Objectives of the Project

The main challenge for the Project can be synthesized on the following: how to design and enact a strategy and tools for assessing the knowledge on health of the Portuguese

¹ The project "Evaluating the State of Public Knowledge on Health and Health Information in Portugal" (HMSP-IISE/SAU-ICT/0003/2009) has started on 1st April 2010.

population, focusing on the conditions² set as priorities for the production of health information materials within the Program Harvard Medical School – Portugal, and how are these materials received and appropriated by specific publics?

Specifically, the objectives of this project are (1) to inquire on the current state of knowledge of the Portuguese population on major health conditions/national health priorities; (2) to provide an assessment of the state of access to health information, its publics, sources, interpretations and effects on health-related practices and (3) to design and test an approach for assessing the efficacy and effectiveness of actions in health information concerning three conditions: colo-rectal and breast cancer, asthma and child obesity.

The study design of the project also involves the (i) development of a heuristic model of how subjects become patients, experience disease and encounter biomedical information; (ii) design of approaches and tools which allow us to follow the trajectories associated with becoming a patient and encountering and appropriating medical information and (iii) collaborative monitoring and assessment of the ongoing production of materials by the health information projects aimed at target publics;

The relevance of narratives of illness experience

The empirical focus of the project is on the explanatory models and semantic networks associated with the knowledge configurations emerging from patient's encounters with biomedical knowledge and health care practices, the chains and mediations of communication on health and how health information is appropriated by respondents (Kleinman, 1989; Groleau et al. 2006).

Considering the strong ground of ethnographic work in the project, we seek access into how individuals construct the meanings of their experience of illness. Thus, although it is assumed that the speech of the individuals is logical, coherent and rational, the narratives that people use to explain their illness and symptoms consists of multiple

² The three conditions developed within the project (cancer, respiratory diseases and childhood obesity) where defined as priorities under the National Health Plan.

representations that can be systematized as (1) based on *explanatory models* of illness and causal reasoning, such as the relationship between symptoms and causes of disease; (2) representations of *prototypes* based on the experience of their illness, or others, to establish analogies between his disease and the other through a logical rationality; (3) representations organized in temporal sequences or *complex chains* in which the experiences and events appear metonymically linked to the current health problem without, however, exists any causal relationship or a logical reasoning (Grouleau, Young and Kirmayer, 2006).

The narratives about the experience of illness not only provide unique material to explore how individuals make sense of it, but also allow access to their explanatory models and prototypes (Kleinman, 1989), around which they constitute and bind their experiences to biomedical knowledge. Narratives incorporate schemes and personal ways of thinking about disease, but also define a position within a particular social context (Stern and Kirmayer, 2004), allowing thus access to a heterogeneous repertoire of cultural resources, which includes the vocabulary and biomedical knowledge.

Strategy and Research Procedures

Despite the recent development of critical and innovative approaches in information and communication on health, the knowledge of how information is received and appropriated by the people, as part of existing configurations of knowledge and, in particular, knowledge based on personal experience, is still limited. Moreover, the ways in which different groups use, evaluate, make sense and combine hierarchized information from different sources or, in other words, the performative effects of information, need a systematic study.

The theoretical and conceptual contributions of this project stems from several disciplines and areas of research, including studies of communication in science and health, social studies of medicine and health, medical anthropology, psychology, sociology of health and epidemiology and public health. It focus mainly in the forms, contents, flows, mediations and modes of appropriation and use of information on

various diseases and conditions included in the project, their diagnosis and therapy, taking into account the influence of biological, environmental, social, economic, cultural and institutional determinants.

Through the narratives we seek to explore new approaches to the experience of illness, and particularly to focus on what is the multiplicity and uniqueness of experience, using a method called *sampling for range* (Small, 2009). Instead of seeking statistical significance, cases are selected for interviews trying to cover a variety of situations associated with a specific pathology. Thus, it becomes possible to explore the different ways in which experiences and trajectories of the subjects emerge regarding the disease. The principal methodology used in the project is a schedule for intensive, semi-structured interviewing on the status of knowledge and of access to and uses of information on health was designed, based on a revision of the McGill Illness Narrative Interview (MINI), a flexible tool which is widely used in social scientific research on health.

MINI is an interview schedule which is divided into a common core of modules aimed at eliciting narratives of the experience of the subject in relation to a specific condition or set of conditions and at inquiring, through a set of structured questions, into the way the subject constructs knowledge of the condition (through prototypes or explanatory models, for instance). Additional modules can be added, on therapeutic experiences, relations with health care services and professionals, or on information (sources, pathways, hierarchy of credibility, appropriation and uses), among others.

This instrument allows a detailed characterization of what counts as knowledge on health for subjects, as well as of the patterns of description and explanation of disease/disorder; the vocabularies used to refer to certain conditions (which are of particular interest for defining pathways for accessing information on a website, for instance); and changes in patterns associated with access to information and to its uses. The interview schedule was adapted for each of the conditions of interest to the Project, and it was complemented with guidelines for interviewing. The latter are particularly relevant for the training of interviewers.

Preliminary Results

During the first six months of the Project the team has worked on a heuristic model of the processes of knowledge formation on health and of changes in knowledge associated with information, its uptake, processing and uses - this was based on an extensive literature review of work on science and health communication, social studies of medicine and health, anthropology of health and medicine and social and clinical psychology.

Fieldwork allowed us to identify and characterize: in detail, (i) what counts as health knowledge for patients; (ii) what are the different patterns of description and explanation; (iii) different experiences of living with the condition and the engagements with health care services and health professionals; and (iv), the different forms and strategies for managing the disease. As an example, we can assert that in the case of asthma, people learn to “manage” their illness, even though there are rules given by the practitioner of how to react under which circumstances. The fact is that in most of the cases, self-management becomes an issue of particular relevance, namely if we take into account the existence of a ‘chronic disease paradigm’ associated with asthma. This means that, to some extent, the management of the disease by the affected individual combines some plastic boundaries between individual control and medical knowledge, therefore distributing personal experiences of asthma through a large spectrum of possible interactions.

In the case of breast cancer, it is clear that the mere availability of information to patients does not prove to be effective. Not only information forms and contents are evaluated, hierarchized and interpreted in different ways, due to individual’s differing social and cultural backgrounds, but also the ways in which people manage information (both in terms of content and timing) are quite heterogeneous. Personal resources, life perspectives, support, access to caretakers and illness trajectories are some key elements brought into discussion by the MINI that define, quite faithfully, how patients mobilize their own resources and vocabularies to deal in the most appropriate way with their illness.

Finally, these repertoires of illness, translated into narratives, constitute a valuable resource to evaluate individuals’ contexts, vocabularies, and their relation to biomedical

services (and other types of medicine) that ultimately epitomize social and cultural frames.

References

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