

# *METHOD AS RESPONSIBILITY IN APPLIED RESEARCH*

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## ABSTRACT

Health literacy has become a key-element of public health promotion – rising as a discipline, a career and even a transactional value – and a variety of professionals have assembled around it. This paper departs from the divergent notions of health knowledge that such heterogeneity entails. Embracing a patient-centered and narrative-oriented approach, our objective is to problematize the ways in which health knowledge has been conceived in common health literacy approaches, and explore unconventional in-depth assessment strategies. Drawing from our experience of working in a literacy assessment project focused on asthma, cancer and child obesity, as well as John Law’s ideas about the onto-political dimensions of method, we argue that selecting a methodology entails an important responsibility of the social researcher in constructing reality, in this case in enacting a particularly consequential definition of health knowledge. Here, we reconstruct the steps through which the project’s methodology was developed, with emphasis on the adaptation of the McGill Illness Interview Schedule. We also present some of the project’s results and point to future directions. Asking what it means to know about health and what the role of social science should be in studying health knowledge, the ultimate goal of this paper is to contribute to the discussion on how applied research can be intellectually, ethically and politically responsible.

## Introduction

The proliferation of national campaigns, philanthropic projects, graduate programs, and job offers related to health literacy and health communication points at the recent rise of a paradigm and practice regarding the promotion of populations’ health (Rudd et al. 2007)<sup>1</sup>. Roughly defined as the capacity of individuals to obtain, process and understand basic medical information (WHO 1998:10), health literacy has become an important concern of the philanthropic agenda. This concern has led to the spread of health education projects worldwide, varying from short-term intensive campaigns to the constitution of more enduring literacy foundations. Health literacy has also become a concern for comprehensive international institutions such as the United Nations

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– with programs in Angola, Vietnam, Mexico, etc., where it has been often discussed as a human right (Murthy n.d.) – but also, as concerns the scope of this paper, for national health agendas in the so-called developed world.

With the rise of health literacy as a public health concern, new forms of expertise emerge and give shape to what is still a fairly grey zone of knowledge and practice. Professionals from very different backgrounds assemble around health literacy initiatives: natural scientists with MAs in science communication, physicians, public health experts, public relations majors, psychologists, sociologists, anthropologists, etc. The relative newness of these initiatives poses a challenge to these professionals, inasmuch as they may have different views about which might be the right strategies to improve the level of health literacy of a population, or even disagree on what constitutes adequate knowledge on health. Communication and consensus among these teams is not always easy. Concurrently, these groups are frequently pressured to produce quick results and simple, clear guidelines, as these initiatives cost money and funds are limited. Thus, the research required to attain context-specific solutions for health literacy improvement is sometimes dismissed in favour of more general, one size fits-all approaches.

Being a social researcher working on these initiatives can be a complicated task. This follows in part from the practice of asking sociologists and anthropologists to evaluate the efficacy of these health literacy projects without having consulted them previously for their planning, as it was the case of this research project. This means that, in becoming applied social researchers, sociologists and anthropologists are often expected to comply with models and strategies that were already discussed and defined as the best option, evaluate them in the field, and contribute with only minor adjustments. This poses an immediate difficulty to the social researcher who is trained in complex cultural dynamics, such as the ones implied in the relationship between patients and caregivers, patterns of knowledge acquisition, and social networks, as well as in critical thinking and multiple schools of method – all skills that would have been useful for creating an adequate strategy for health communication when the program was in the planning stage.

A major question arises from this: what should be the role of the social researcher within these programs of social intervention? At a first glance, it may seem that there are only two possible solutions: either the social researcher blindly abides to the contract and performs his/her task thoroughly, or adopts a critical posture that may sometimes be confounded with antagonism. Nevertheless, this is no ordinary quandary, and we believe the answer may involve various shades of gray, rather than an option between black and white. This problem, which itself is part of a larger debate about the role and ethics of applied social research, deserves

our fullest attention, in that it ultimately involves issues of professional competence and intellectual honesty.

How then to perform as an applied researcher and keep the critical thinking necessary to make a difference in ameliorating these programs and campaigns? How to remain faithful to your disciplinary allegiances while working on assessing the efficacy/effectiveness of these initiatives?

This paper addresses some of these quandaries, and it aims to explore how research can be ethically, politically and professionally responsible through the conscious selection of concepts and methods. Using health literacy initiatives as a background, we will be thinking from the perspective of two junior researchers working in an evaluation project directed at health knowledge and medical information. In response to the lacunas of the overly individualistic and biomedical-centred definition of health knowledge as it is usually adopted by common health literacy initiatives, the project "Evaluating the State of Public Knowledge on Health and Health Information in Portugal" developed a sophisticated version of this notion, believing that this will constitute an important contribution to the field of health literacy. This requires alternative methods of assessment in order to help improve the quality and adequateness of its interventions. The argument will unfold in four sections. The first addresses what it means to know about health, and provides a theoretically sustained critique on the definition of health knowledge usually privileged by professionals and institutions working in health literacy initiatives. The second, how to assess health knowledge, explains the process of developing a methodological strategy in the view of the notion of health knowledge adopted in the project. As we will further see, empirical qualitative methods were crucial in delving into what is still underexplored territory within health literacy studies. Then, in the third section we will present some preliminary results from interviews conducted with asthma patients in order to illustrate the kind of evidence our methodological approach has helped us to consider. Lastly, we will comment on our experiences as junior researchers working in this project and make some considerations about the importance of adopting alternative strategies when the goal is to generate alternative realities.

### What It Means To Know About Health

The literacy effort is based on the aim of improving the overall population's health by enabling individuals to make rational decisions affecting their health through access to medical information, its interpretation and use, in ways that are consistent with what the biomedical establishment defines as accurate (WHO 1998). Despite the radical transformative ambition of the project of health promotion through literacy, much of these programs' energy appears to be exhausted in narrow

initiatives that overlook the heterogeneous positioning of its recipients, and thus fail to attain their objectives. One example of the non-sensitive strategies that dominate the practice of health literacy is the variety of websites offering medical information. As part of national agendas, large investments have been made in providing citizens with these virtual information platforms. In the case of Portugal, this has been happening through a partnership between the Portuguese Foundation for Science and Technology and the Harvard Health Publications.

“Evaluating the State of Public Knowledge on Health and Health Information in Portugal” is a project funded by the Portuguese Foundation for Science and Technology within the Harvard Medical School-Portugal Program in Translational Research and Information; a Program which, as the name indicates, has as its main goals the improvement of translational research and health information in Portugal. The Program assembles several different projects, some of which were engaged in the construction of information for a website along the lines of <http://www.health.harvard.edu/> of Harvard Health Publications. Throughout the first two years of the Program, our project, one of the few in the Program led by social scientists, was expected to provide an evaluation of both the baseline of knowledge on health by prospective users of that information and some of the information materials produced for that virtual initiative, focusing on three health conditions: asthma, cancer (breast and colorectal) and paediatric obesity. Though the aim of creating a fully dedicated website was recently abandoned, some lessons can be extracted from the process.

The Project's initial challenge was to achieve a strategy for assessing the health knowledge of the Portuguese population, particularly in respect to the materials that were being produced within the Harvard Medical School – Portugal Program. A key point of interest concerned the ways in which these materials would be received and appropriated by specific publics – whether these were individuals diagnosed with a condition, informal caregivers, young or old, internet users, college students or people who cannot read or write (which unfortunately is still a problem in Portugal, especially among the elderly living in the most rural areas (INE 2012:21) –, knowing that how this appropriation happened would depend on what was pre-known by them (Nunes 2014).

Following what has been said about how health literacy is defined by institutions and professionals working in the field, health literacy initiatives and measurement tools commonly put emphasis on the individuals' ability to understand medical terms and baseline information related to medical prescriptions and exams, prevention of diseases and self-care (WHO 1998). Popular instruments such as the Newest Vital Sign (NVS) (Weiss et al. 2005), the Rapid Estimates of Adult Literacy in Medicine (REALM) (Murphy et al. 1993), and the Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al. 1995) are good examples of this emphasis. The first two are quick screening tools that take two to

three minutes to administer and score. Quoting Pfizer Inc., the NVS creator, “The Newest Vital Sign is based on a nutrition label from an ice cream container. Patients are given the label and then asked 6 questions about how they would interpret and act on the information contained on the label.” (Pfizer Inc. 2012). TOFHLA, despite being longer, is equally focused on reading and numerical comprehension in a closed questionnaire. Usually conducted in clinical setting by health care professionals, these instruments epitomize the kind of knowledge health literacy initiatives have been privileging, a knowledge that is almost exclusively defined by the biomedical canon and excludes other rich experiences of things such as what it means to be healthy, sick, or be cared.

According to recent surveys, the levels of health literacy in Portugal appear to be one of the lowest in European Union countries (study by the Institute of Social Sciences, Portugal using NVS, forthcoming). However, as Shannon Carter puts it, the significance of this kind of deficit “...is determined less by need and more by the value society places on the area in which we may be considered literate (or not), as well as the measures used to determine "literacy" (or illiteracy) in a given area...” (2008:34).

There are good reasons to challenge the common criteria in use for defining health literacy, and adopt an alternative conception of what counts or should count as “lay” knowledge about health. The fact is that most of our repertoires of beliefs and attitudes towards health and illness are constructed outside the canons of biomedical thought. This does not mean that these beliefs and attitudes are necessarily “wrong”. As a matter of fact, many of these beliefs lead to what would be regarded by the biomedical establishment as correct practices. What this fact does mean is that much of our understanding of health and illness does not build on knowledge about etiologies and scientifically sound terms. And if medical efficacy is a criterion for defining knowledge on health, then a biomedical definition would surely not exhaust the range of possible forms that this knowledge can have.

The tools mentioned above are also insufficient for grasping social dimensions of learning and knowing about health, being descriptively sterile at this level. They are prone as well to the risk of [re]producing class, gender and race-based asymmetries regarding “good” and “bad” health subjects, or enlightened versus non-enlightened. In this regard, the notion of the “violence of literacy” recovered by Shannon Carter in her critical inquiry into English teaching recalls us that the general notion of literacy reflects neither an individual skill, nor, in many cases, a *sine qua non* for individual success (Carter 2008). Literacy is social, not individual, as it is constructed and acquired through interpersonal interaction in particular environments where skills and modes of thinking may be differently celebrated and promoted. This negligence of the social matrix of literacy is then aggravated when these oversimplified standardized closed tests travel and get administered in contexts where their contents do not even make sense, literally

speaking, to respondents. This is the same critical argument which has so often been addressed, in the past, to IQ tests (Gould 1996).

Even within the same socio-cultural context, studies in cognition suggest that knowledge is not stable and continuous across settings and themes, and that people tend to think about health-related issues drawing on anecdotes and analogies, rather than by proceeding deductively from previous normative-prescriptive knowledge (Freythuth, Ronan 2004; Lave 1988). It follows that there is a broad range of forms of knowledge on health and illness which are usually elicited only in particular situations. It also follows that enunciation will never be sufficient to grasp the universe of these understandings and the ways in which they are formed and used. These properties per se pose important challenges for studying knowledge of any kind on any topic. Regardless of the limits of such endeavor, which is naturally destined to partiality and incompleteness, there are strategies for embracing this complexity in social research.

Anchoring the Project in a plural set of thought traditions within the social sciences – including studies of communication in science and health, social studies of medicine and health, epidemiology, public health, cognitive anthropology, new literacy studies, medical anthropology and sociology of health – helped to problematize health knowledge as such and to develop a more sophisticated view of its possible contents and sources. This view includes not only what is defined by the biomedical establishment as appropriate knowledge about health and illness, but also popular beliefs formed and acquired through multiple vectors throughout the life-course – at school, with family and friends, through the media, in interaction with health care professionals, and so forth. As we will further see, “lay” knowledge on health is formed and acquired through a plethora of circumstances that include various sorts of interpersonal interaction crisscrossed by codes of power, trust, and attachment. Moreover, as medical anthropology teaches us, illness is probably one of the most private experiences and yet one of the most social too, at the same time (Augé 1984; Schepher-Hughes, Lock 1987). Then, this knowledge, which is partly constructed in interaction with others, is also the product of intimate impressions of what it means to be sick and what one can do regarding one’s own condition. This means that experiential dimensions of health knowledge construction should also not be disregarded.

Given this complex portrait of forms and networks of health knowledge formation and acquisition, the main challenge of the Project matured. The question of how to do an assessment of the health knowledge of the Portuguese population became how to do it in a way that would do justice to this vision. Methodological options towards the inclusion of the widest range of publics, sources of medical information, and kinds of health knowledge had to be made.

## How to Assess Health Knowledge

Choosing a definition of health knowledge that includes plural groups of individuals (sick and non-sick, of different ages, with different conditions and from different social backgrounds), sources of health information (from the internet to the doctor, friends and family), as well as different types of health knowledge (whether of a biomedical, popular or experiential kind) is itself a statement about the social reality the researcher aims to study. Following John Law's observation on how social research has tended to neglect the world's intrinsic messy character, it is important to note that methods always imply selection (of objects, of frameworks and concepts, of categories of analysis and indicators), and so they constitute particular ways of inquiry generating specific ways of seeing (Law 2006). By cleaning up the mess, or reducing the complexity into linear, tidy stories, which are ideally free from ambivalence and incongruity, for Law, methods are constitutive of social order and reality, rather than reflective of them (Law 2006). Hence, method has what we may call onto-political implications in the world. Law also suggests that this may be regarded as a productive feature, rather than a blocking critique of social research. He thus calls for the development of alternative ways of approaching social reality, ways in which this messiness gets elicited and complexity is embraced. From our perspective, this onto-political character of method implies that the responsibility of the social researcher should always be kept in mind. That is to say, method is a way of enacting the researcher's responsibility, her contribution to making a difference in the world.

To do justice to the complex notion of health knowledge adopted, and given the fact that patients have traditionally been excluded from the production of medical information, the project's concern became to create a space for listening to patients and allow them to account for their experiences of health and illness and of engagements with medical knowledge, the health professions and health care services in their own terms, thus problematizing the view according to which they are regarded as compliant recipients of information and medical prescription.

As this project involved sociologists, anthropologists and one communication expert, it had a cross-disciplinary character that made everyone familiar with the advantages and disadvantages of both quantitative and qualitative research methods of social research since its beginning. Though the team does not believe in a dichotomous or mutually exclusive relationship between the two, preferring the Miles-Huberman notion of methodological continuum (Lessard-Hérbert et al. 1994), empirical qualitative methods offered a more interesting approach to what was considered underexplored territory within health literacy studies as it was previously addressed. After all, qualitative methods allow the kind of exploratory engagement with reality through which the researcher can be surprised with new questions and hypotheses that were not predicted at the time the

initial problem was defined (Becker 2004). They rely less in pre-established indicators than their quantitative counterparts. Likewise, qualitative approaches are most suitable for the creation of a grid of analysis from the agents' point of view (Becker 2004; Quivy and Campenhoudt 1998), in this case the patients' point of view.

Listening to the patients in a semi-structured interview would then be a solution for going beyond a normative and pre-established notion of health knowledge, or avoiding using biomedical knowledge as the yardstick to measure health knowledge and literacy. Besides that, there was also the intention of focusing multiple patterns of medical information acquisition, instead of limiting the study to the media or the internet, which only an in-depth interview could grasp. Using narratives of illness experience (Kleinman 1989) became the heuristic selection/solution for responding to these requirements that derived from the object "health knowledge".

The project's main methodological tool is now a schedule for intensive, semi-structured interviewing on the status of health knowledge, and access and uses of health information developed from the McGill Illness Narrative Interview (Groleau et al. 2006).

The McGill Illness Narrative Interview (MINI) was designed to structure an interview of about one hour focusing on three rhetorical or cognitive structures used by patients for illness sense-making: (a) the explanatory models of causal reasoning, such as the attribution of causes to disease's symptoms in an etiological fashion; (b) the prototypes based on others' experiences of illness acquired mostly through interaction with family and friends, but also through the media and popular anecdotes, which are then used to explain one's own experience through analogical reasoning; (c) the complex chains in which experiences and events appear metonymically linked to the patient's current health problem without, however, mention of a causal relationship or explicit logical reasoning connecting them (Groleau et al. 2006).

Beyond a core of modules aiming at eliciting narratives of the experience of the subject in relation to a specific condition or set of conditions, and at inquiring into the way the subject constructs knowledge about these conditions, additional modules can be added to the MINI (Barradas et al. 2012). This flexibility allowed the inclusion of a section on the relation to access, sharing and use of medical information. It also allowed us to make some minor adjustments in relation to each condition under study. And because MINI's initial module consists of an open narrative, this tool has also proved to be adequate to explore a diversity of biographical trajectories, and their differentiated attachments to family, community and the world of health care, including both biomedicine and other forms of therapy and healing.



Therefore, narratives of illness experience collected with MINI not only provide unique materials to explore how individuals make sense of their condition and experience it, but they also enable us to grasp how their explanatory models and prototypes bind their experiences to biomedical knowledge and other kinds of knowledge as well. This is so because narratives are more than idiosyncratic schemes. Narratives are cognitive and communicative devices acquired and developed through social processes, thus echoing particular contexts (Stern, Kirmayer 2004). Considering the narrative in its double horizon – the narrative itself and its relation to a particular referent – these are means to understand both individual experience and context. On this subject, the team has also been attentive to the relationship between particular types of narratives and the specific conditions at study (Frank 1997).

Once the problems of including different types of health knowledge and its forms of acquisition were solved, there was still the issue of selecting individuals for interviewing in a way that would allow an alignment with the principle of heterogeneity of publics which was stressed before. Sampling for range (Small 2009) was the strategy adopted for making the set of cases selected for analysis as rich as possible, in consideration of the multiplicity and uniqueness of the experiences collected. Accordingly, instead of seeking statistical significance, cases are being selected with the intent of covering the largest possible variety of situations associated with the health conditions we are focusing on.

Sampling for range allows for a deliberate selection of cases for either maximizing commonalities of experiences/trajectories or maximizing the range of differences in experiences/trajectories, regardless of how frequent these may be. The rationale behind looking for differences is that unusual or “rare” situations or experiences provide insights into the processes of interest which would go unnoticed when searching for commonalities, and which may reveal mechanisms or relations which help in clarifying the processes of interest. This is a time-honoured way of proceeding in qualitative social research, which provides significant insights complementary to survey-based procedures (Small 2009). In this case, this approach was enacted through focused sequential interviewing.

### A Preliminary View On The Interviews With Asthma Patients

Here we draw on a first set of thirty-two interviews conducted with patients from Hospital São João in the city of Oporto, Portugal, in 2011-2012. Interviews were on average fifty minutes in length and they were conducted so as to encourage people to talk about their experiences with asthma throughout their biography, letting their stories breathe, so to speak (Frank 2010).

Though the project is in its beginning and this analysis is preliminary, the following paragraphs explore some of the individual trajectories and experiences – of illness, and of knowledge use and acquisition – that will feed our further investigation. A more exhaustive analysis can be found in Ana Filipa Queirós master's thesis *Respirar cuidados: contributos para uma análise sociológica das narrativas de experiência das pessoas com asma* (Queirós 2013).

*“Everyone has at least a family member who has asthma – a relative, a brother, an uncle, or a cousin who has asthma –, therefore everyone deals with it normally”.*[DR, male, 34years old]

It is common to find patients whose father, mother, or other family member(s) suffer or had suffered from respiratory diseases. According to our interviews, this is a major reference in learning how to deal with the disease, as someone else’s experiences sometimes serve as prototypes for understanding one’s own. In these cases, patterns of causal explanation follow the hereditary logic, and people put emphasis on asthma as a “family issue”.

As evinced by the interviews, concerns with the kind of information an asthmatic should receive from health care professionals appear to be constant, regardless of having family members with the same problem or not. Most of these patients are willing to control their disease, to prevent it, or to learn what to do when a crisis starts, and thus, at least ideally, to incorporate the management of the disease as part of their habits and routines. For some, knowing “their asthma” is a critical aspect of this management.

**Interviewer:** *And the information they gave you in the first visit, was it enough to know your disease better?*

**Interviewee:** *Yes it was. And you know why? I immediately started to adapt to it and try to put away suffering. I started thinking “this is it, I will follow this treatment, I will get used to it, to feeling it”, and I feel the crises... when they start, I detect them right away. It's still far away but I know I'm going to be sick, and that's for sure.* [CRM, female, 56years old]

Personal narratives have also highlighted different experiences of living with asthma, suggesting a heterogeneous set of profiles that may be partially connected to gender, age, education, profession, and role within the family. This heterogeneity is particularly noticeable when it comes to accounts of suffering.

*“People understand it. It’s nobody’s fault for being sick”.* [M’s wife, >70years old]

Though asthma is often dismissed as a condition which is not severely disabling, several interviewees mentioned experiences of suffering, incapacity and frustration arising both from the side effects of medication and the nonspecific somatic complaints associated with the condition – i.e., complaints that are not directly traceable as asthma symptoms, such as frequent cough, sneezing or feeling tired. These “light symptoms of asthma” are worth mentioning in that they vary a lot in how they affect our interviewees’ lives. Testimonies of how the performance of simple daily tasks was compromised by these light symptoms are frequent among women. In some cases, this incapacity caused by asthma appeared associated with considerable psychic suffering.

*“Now I’m more careful and my husband helps me, he says “give it to me, I’ll do it!” [dusting]. But before I would do it, I liked to do it myself. And now, if I do it, I wear a mask, but even so it still affects me (...)” [DM, female, 59years old]*

*“I feel very sad; I have been feeling very bad, I’m taking antidepressants and all that, because I feel so useless. I even say to my husband that I am not doing anything here, I am useless because I cannot work, and there is nothing I can do... I really don’t know”. [SM, female, 52years old]*

For both men and women, being regarded as lazy, weak or vulnerable for avoiding specific tasks because of these silent discrete symptoms was also a major source of concern.

*“Yes, to cut and pull the weeds, I can’t. I immediately start to get a sore throat. Then, it seems like I start losing my breath, I sneeze a lot... And there are certain things that I cannot do outdoors. Well, I already knew that. But one tries it anyway. You will not stand still watching others working, right?” [OP, male, 35years old]*

Still, when asked directly about whether the condition changed the way they see the world and themselves, people tended to downplay the life-changing effects of asthma. The assertion of normalcy is an essential aspect of a significant number of the narratives we have collected. As Arthur Frank would put it in *The Wounded Storyteller* (1997), these are “restitution narratives”, the kind of narratives that allow people to assimilate their condition into their worldviews and routines, and to adapt to it the best way possible, in a socio-cultural context marked by the values of independence and autonomy. This solution is also encouraged by the health

institutions and the health care professionals by framing asthma within the paradigm of chronic disease, of (self-) management and treatment.

At this level, another cluster of heterogeneous profiles may be found, as different people find different forms and strategies for managing asthma. Even though most of the patients have access to medical information through practitioners, learning how to deal with their asthma draws on the plastic or porous boundaries between the medical knowledge that is communicated by the professionals and the knowledge already held by the individual. This individual knowledge might be informed by his/her experience(s), others' experiences understood as prototypes, popular knowledge, etc. This means that there is a multitude of possible consequences of medical information on patients' behaviour. Further work on the close relationship between different patient trajectories and profiles of knowledge acquisition and use, following a differential analysis with cancer and child obesity cases, is our current project.

*“When I'm playing football [with friends at school] and I feel it a little bit I say “hey, I'm out because of the inhaler, I'm going to use my inhaler now!”, and they say “no, no, you stay in the game!”, and I say “no, I won't!”. And then I go to the bathroom, I do it, and then I come back.” [R, male, 10years old]*

## Conclusion

From the junior researcher standpoint, participating in the “Evaluating the State of Public Knowledge on Health and Health Information in Portugal” Project has been a challenging experience. Not only the project has provided us with professional insight and training, but it also has put us in contact with the tensions that may arise between different schools of thought and method in social sciences at a fairly early stage of our careers. Understanding the predicaments or the dilemmas to which those tensions may lead has raised our awareness to the intricacies of conducting applied interdisciplinary research, both in terms of its frictions and its potential. It has also made us rethink the boundaries that we have previously taken for granted, namely between professional, ethical and political dimensions of social research.

To avoid reproducing a notion of health knowledge and literacy that did not seem to respond to the objectives of the Project and to central features of Portuguese reality was a deliberate intention that got translated into the concepts and methods adopted. Understood as heuristic openings, or analytic lenses, to use a more familiar analogy, conceptual and methodological options produce particular ways of seeing which should not go unnoticed and deserve close reflection. The team took this as an important responsibility inherent to the social researcher's work: to make sure one completes his/her task with excellence without disregarding critical thinking

towards the objects of study and the possible impacts of research, as well as his/her own particular perspective as an intellectual about which one must try to be clear and thoughtful. Though the questions about the ethics of applied social research are not new, these are predicaments which may gain new relevance, as the number of social scientists working for consultancy companies and doing applied research increases, and research policy and funding institutions privilege social science as a means for understanding social behaviour and intervening to change it. As the demand and supply of social researchers performing technical tasks increase, how to keep a commitment to ethical research and critical thinking may be a question to put under the spotlight again.

Empirical qualitative research based on personal narratives collected through in-depth interviews would thus not be the only way of investigating “lay” health knowledge, but a thrilling approach that has been enabling us to grasp: (i) what counts as health knowledge from the patients' point of view; (ii) what are the different patterns of illness description and explanation, including explanatory models, prototypes and complex chains of biomedical, popular and experiential matrix; (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. All involve a perception of life-course variation, or of biographic time depth, about which interviewees themselves provide reflections when so asked by interviewers. From here, we expect to develop specific strategies to fit these different needs and demands. These strategies will cover not only the contents and language medical information on asthma, cancer and child obesity should observe, but will also put forward suggestions regarding new ways of thinking health literacy interventions and assessment tools.

The whole process has an interesting transformative quality for both the researcher and the interviewee. For someone trained in anthropology, a discipline in which fieldwork and immersion is foundational, this transformation is somehow expected. Anthropology was born from the principle that only empathetic engagement could bring understanding of others' cultures or ways of seeing the world. Learning the language and living for a long period among the ones one studies with was part of the method. Self-transformation has been understood as a constitutive part of anthropological inquiry. For a sociologist, this has not always been the case. Nevertheless, ethnography and qualitative in-depth methods are nowadays a much more common practice among sociologists and other professionals, including communication experts, psychologists, and health professionals, than what it used to be, used both to generate categories of analysis, and as a method on its own. On the other side of the equation, interviewees themselves are often transformed by the self-reflexivity these interviews entail (Charon 2008). Such an approach is definitely arduous. It not only requires the researcher to be observant, patient and empathic in ways that sometimes can be

very intense and exhausting, but it can also be a very time-consuming style of research. However, we believe in the importance of keeping up with these qualitative ethnographic-based studies along with the traditional, statistical-based methodological approaches within literacy studies and public health. This is so even if (or especially because) these fields are dominated by expectations of quick and generalizable results. The way we see it, qualitative research is not averse to rational management of resources. Quite on the contrary, it may serve the creation of very rationally attuned public health and literacy solutions for specific contexts.

## Notes

<sup>i</sup> This paper was firstly submitted to vis-à-vis: Explorations in Anthropology in March 2013, and it draws on research materials from that date. The research is part of a larger project titled “Evaluating the State of Public Knowledge on Health and Health Information in Portugal”, funded by the Portuguese Foundation for Science and Technology within the Harvard Medical School-Portugal Program in Translational Research and Information (HMSP-IISE/SAU-ICT/0003/2009-FCOMP-01-0124-FEDER-013012, 2010-2013), which was concluded in the same year. The final results are expected to be published as a book in the upcoming months (Nunes 2014). We would like to thank João Arriscado Nunes for helping us refining our thoughts at a final stage of this paper, as well as the rest of the research team for their various contributions.

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