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From silence to evidence based-activism: the epistemic and political empowerment of the Portuguese Stuttering Association

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Abstract

Science and Technology Studies have shown the virtues of moving from Public Understanding of Science to Public Engagement with Science. Experiences of collaborative participatory research and community-based participatory research reveal some of the complexities related to both science/society relations and science/democracy relations. These are characterized by the engagement of scientists and civil society organizations in the resolution of problems of common interest and in the development of innovative projects with social impact through the promotion of egalitarian and nonhierarchical epistemic relationships between them.

This paper aims to put forward some reflections resulting from the collaboration between the Centre for Social Studies and the Portuguese Stuttering Association. The collaboration seeks to promote strong dialogues between people who stutter, speech-language pathologists, psychologists, experts in neuroscience, linguistics, among others, in order to foster a reflection on stuttering, its causes, possible coping strategies and different legal and clinical frameworks. More precisely, the purpose of this paper is to reflect on the potentiality of this collaborative device to promote the epistemological empowerment of people who stutter, allowing their emergence as "experts of experience" (Rabeharisoa & Callon, 2004) and owners of relevant knowledge about stuttering, giving them the legitimacy to participate in the collaboration, not as objects of research, but as active subjects of knowledge production, capable of developing an "evidence-based activism" (Rabeharisoa *et al.*, 2013).

Introduction

Science and Technology Studies have shown the virtues of moving from Public Understanding of Science to Public Engagement with Science. Experiences of collaborative participatory research and community-based participatory research reveal some of the complexities related to both science/society relations and

science/democracy relations. These are characterized by the engagement of scientist and civil society organizations in the resolution of problems of common interest and in the development of innovative projects with social impact through the promotion of egalitarian and nonhierarchical epistemic relationships between them.

The collaboration between the Portuguese Stuttering Association (PSA) and the Centre for Social Studies (CSS) being held under the project Biosense "Science Engaging Society: Life Sciences, Social Sciences and Publics"[1], will be at the core of this paper. The project Biosense aims at the creation in Portugal of a Science Shop, and with it, the promotion of a new form of science/society relations through the engagement of science with a variety of publics concerning issues with social implications. Science shops are organizations that offer citizens groups and Civil Society Organizations (CSO) free or very low-cost access to scientific and technological knowledge and research in order to help them achieve social and environmental improvement (Jøgersen, 2003: 1). The major responsibility of the Biosense project's team was to identify the knowledge needs of the CSOs that contacted the Science Shop and to promote the constitution of collaborative partnerships between CSOs, scientist and research unit considered relevant for an effective co-production of knowledge that responded effectively to the need felted. The mediation and facilitation work needed for these alliances in order to promote this access to research and knowledge was a significant part of the work done by the Biosense team and involved the active engagement of Ph.D students in each collaboration.

The development and analysis of the collaboration between the PSA and the CSS is part of my doctoral work named "Dialogues and Translations in Collaborative Research Practices", specially the analysis of the conditions that allow the development of the alliances needed in a democratic mode of knowledge production. The main research interest driving my work is on how these collaborative participatory research projects can stimulate a radical co-presence (Santos, 2006), an epistemological parity between citizens and scientist in order to overcome the deficit model. Thus allowing community members, CSOs representatives, patients, non-scientist, to become full active

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participants in research projects, contributing in all stages of research, including the use of its results. This raises questions concerning the classic epistemic distinction between experts and lay people, and about the conditions necessary to stimulate this kind of horizontal and pro-democratic interactions between different communities of practice (Lave and Wenger, 1991) specially in a collaborative situation involving not only scientists but also CSO and communities, among others, that we will try to answer during this paper.

Collaboration?

The first of these questions is precisely on what we mean by collaboration. One possible definition describes collaboration as a situation of cooperation in which the actors involved work together on an equal basis with the intention of mutual help in the pursuit of goals that will benefit all those involved (Boavida and Pontes, 2002). In our work, nevertheless, collaboration is far more than cooperation. So, an additional conceptual refinement is necessary. In collaborative work we have a redistribution of ownership and authorship of the work being done between those involved and this includes the products and benefits resulting from this work. In this sense, authority and responsibility are also redistributed. There is no active/passive dichotomy because all participants are engaged actively not only in the work being done, but also in the definition and identification of what is the problem at hand, what are the best possible solutions to resolve it, the necessary steps to do the necessary work, what are the relevant resources to be mobilized during the process, etc.

The relevance of this discussion lies in the type of collaboration here considered, which includes not only scientists - and we have to consider the internal diversity of the scientific community - but also representatives of CSOs, members of communities, patients or afflicted by some condition or problematic situation. Therefore, the focus of attention was necessarily directed to the problematization of the conditions necessary for a communicative and interactive situation of non-reproduction of the deficit model and the power/knowledge hierarchical relations (Foucault, 1980) shaping scientists and citizens' interactions.

This implied that knowledge drawn from CSOs, from communities, from citizens or patients should be recognized not only as a legitimate and relevant epistemological resource to the process of knowledge production, but as a full body of knowledge and practices that participates fully involved in research in his own right. This is quite different from its use as raw material for the production of scientific knowledge, where the definition of what is relevant or not is dictated by the scientist, who decides on its inclusion or exclusion in research work, on the way in which this is done and on what the parameters dictating these choices. The work developed in science and technology studies by author as Michel Callon (1986), Bruno Latour (1988) and John Law (1987) in the analysis of the "translation processes" involved in all scientific work and in the problematization of both the role of scientist as focal actors in the definition of the actor-network and on the involvement and *interessement* of the different entities considered at stake is central for the reflections where proposed.

Given these reflections, and in order to satisfy the conditions being established throughout this initial discussion, there was the need to create a collaborative device that allowed a dialogue based on horizontal and not disqualifying relations between common sense, everyday pragmatic knowledge and scientific knowledge. The definition of these conditions was inspired by the theoretical proposal for science/society and North/South epistemic relations of Santos (2006) for an "Ecology of Knowledge" and by the work of Jacques Rancière (2010) and his postulate of the equal capacity of all to produce knowledge about the world.

Inspired in the work of the French philosopher, we assumed an "equality of intelligences", the equal capacity to produce valid and relevant knowledge by all those participating in the collaboration. This means that the epistemological parity earlier mentioned does not come as a final goal, as a product of a pedagogical process by which someone who possesses knowledge transmits it to someone completely deprived of it. But rather as an initial assumption for the creation of this collaborative device: all involved had the capacity to produce knowledge about the issue at stake. This postulate assumes no initial distinction between scientific knowledge and common sense and pragmatic every day knowledge, considering this distinction as the result of organized social practices. All of the involved know something relevant about the issue at stake.

Instead of focusing on the ignorances we choose to focus on what's known. Whatever forms it may take.

We have already discussed the power/knowledge relations that shape science/society interactions. So the problem that this assumption creates to this work is on how to promote a short circuit on these differentiating social practices. The way we embraced this challenge is described next.

Creating a collaborative device

Focusing the collaborative alliance between the PSA and the CSS, it was assumed a problem-oriented approach, inspired in action research and in community based participatory research methodologies. The collaboration started with a set of preliminary meetings arranged with the intention of identifying a problem, a knowledge need felted by the organization that simultaneously could be translated into a research question that could be answered by the CSS and by me. Thus being simultaneously suitable to the research interests of both the institution and researcher and around which we could structure, support and give a direction to the building science-citizens partnership. In these meetings participated People Who Stutter, Speech-Language Pathologists members of the directive boards of the organization. They were gradually complemented by individual interviews with other specialists and professionals considered relevant. Their identification follows a snow ball methodology.

In these first meetings, according to the needs listed by the PSA, a problem was identified as being able to trigger the collaborative process. The problem could be translated into a question: What is stuttering? The question is quite simple but the answer is not! Stuttering is a complex, non-linear and multifactorial entity, involving and articulating multiple dimensions: genetic, neurological, social, behavioral, psychosocial, among infinite others, with multiple possible entry points and with an increasing number of interesting and fascinating scientific branches and disciplinary combinations. There is a) a controversy about its causes; b) there is no consensus on what treatments are more effective; and c) there is no cure for stuttering.

On the one hand, in Portugal this debate and the scientific and medical research done about this condition is in a very early stage of development. On the other, the PSA

showed an extreme difficulty in presenting an explanatory narrative of stuttering that could support any political demand and thus justify its existence as a CSO representing PWS. And also stressed the desire to strength the ties linking them to the scientific community in order to a) lobbying for greater investment in this research field and, b) actively engage in research projects directed towards the cure and mitigation of stuttering.

So the problem and the question raised were translated into a knowledge need: the organization's need to develop a strong activist position through the elaboration of an explanatory and political narrative of stuttering, rising from the point of view of those who stutter, and to inform and strengthen this narrative – and the following demands, vindications and political and advocacy activism – with privileged close contacts and dialogues with the Portuguese scientific and medical community.

Identified the problem given meaning to the collaboration, identified the research question and the knowledge need, It was then established the main goal driving the collaboration: the creation of relational spaces where people who stutter, speech-language pathologists, psychologists, but also relatives and parents, neurologists, linguistics or teachers, could talk, interact, exchange ideas and experiences, thus promoting a constructive dialogue and a mutual learning environment, based on the democratic premises of epistemological parity and horizontality defined earlier.

In doing so, another intended goal, as we are going to address latter in this paper, was create the conditions allowing a rising proto-activism essential for lobbying for greater research on stuttering, the development of better coping and therapeutic strategies, the questioning the existing different legal and clinical frameworks, among other. The crucial point in this work was the promotion of the organizational, epistemic and political empowerment of PSA.

The multiple nature of stuttering

From a scientific standpoint, this collaborative device could prove to be pertinent by accounting a) the difficulties and complexities of this type of alliances between citizens and scientists, and; b) the complex nature of the object of knowledge itself, stuttering,

shared by several thought collectives (Fleck, 1935) claiming a position of epistemological sovereignty.

Due to this shared nature, stuttering can be analyzed as a boundary object (Star and Griesemer, 1999), an object living in various social worlds. Boundary objects are plastic enough to adapt to the local needs and constraints, keeping nevertheless a common identity across these various social worlds. Due to this unique possibility for contact between those who usually do not interact promoted by stuttering, we have the opportunity to witness the production of ethno-epistemic constructions (Irwin and Michael, 2003) that articulate different actors and entities in hybrid and heterogeneous constructions, involving epistemological, ethical, regulatory, cultural, personal suffering different dimensions.

The different translations at work, the tensions that arise, the commensurabilities and incommensurabilities in progress between different versions of stuttering, complex and multiple in its ontological nature, meaning distinct things for distinct thought collectives, points out to stuttering as an ideal object for the study of the possibility of dialogues between them. The question at hand is precisely the multiple ontological nature of stuttering, ground for a political work of choices to be made (Mol, 2008): what is stuttering? What are the ontological consequences of those choices for the distinct actors involved? Can different versions of stuttering interact? If so what are the consequences? Both in terms of research, for the production of knowledge, but also in terms of the political activist demands raised by the Portuguese Stuttering Association. And, perhaps more important, what are the consequences of those choices in the lives of those who stutter?

Stuttering groups: the creation of relational spaces

In order to answer to some of these questions, the creation of the necessary boundary conditions for bringing to light this multiple nature of stuttering was indispensable. The creation of relation spaces where the different publics interacting with stuttering could meet, dialogue, exchange meanings, lived experiences and theoretical and pragmatic conceptions of stuttering was the adopted strategy. These relational spaces are spaces where different forms of socialization take place, identities are performed, expertizes

are defined, knowledge and world, or more accurately, knowledges' and worlds, are co-constructed. So, especial attention had to be paid to the collateral realities (Law, 2009) taking form around stuttering.

For that purpose, support was given for the creation of two online forums (on *Facebook* and on *Google Groups*). Each one has now more than 140 participants. These forums are described as being «composed by people who stutter, parents and relatives, speech-language pathologists, teachers and other health and education professionals aiming the creation of a "safe space" of reflection and share that will feed a new perception of stuttering among all those who interact and live with it and seek to critically debate it and better understand it».

Secondly, is also being provided support in the organization of self-help/mutual-aid groups. These groups function on a monthly basis and are run and facilitated entirely by PWS. They are named as "Stutter Groups" and are described as «informal group meetings, with extent of 1 or 2 hours, aiming the encounter and share of experiences and ideas between people who stutter. Participation in these groups is free, voluntary and entails no obligation to intervene». At the moment there are three Self Help/Mutual Aid groups fully operational in Coimbra, Porto and Algarve. One is staring in Lisbon and three more are being planned in Guimarães, Leiria and S. Miguel. Participation is these groups fluctuate between 4 to 12 people per meeting.

And finally, it was provided support in the organization of the 5th and 6th Conferences about Stuttering, the first on "The Right to Stutter", the second called "Breaking Silences, Sharing responsibilities". The main goal was to discuss, in a formal communicative context, the multiple nature of stuttering. To this purpose, there were invited national and international specialists from various fields of expertise to discussions with people who stutter, the latter participating on an equal basis, making presentations, taking place on stage as legitimate and relevant speakers to share their experiences and tell their own life stories, as opposed to the more theoretical interventions of the credential specialists.

From silenced victims to proto-activists

The creation of these relational spaces had the following purposes:

First, to create the conditions for PWS to share their personal experiences and testimonies, promoting discussion concerning common features but also idiosyncrasies, commonalities and singularities in the lives of those who stutter, reflecting on what are the possible ways of understanding and experiencing stuttering. This could allow, and indeed allowed, an emerging perception of stuttering not as an individual problem or condition but as a collective and social problem, thus allowing a political awareness and the consolidation of community ties around a collective identity and a collective, based on experience knowledge of stuttering: an "experiential knowledge" (Borkman, 1976). If this generalization dynamic is crucial in the constitution of stuttering as question of public concern, consolidated by the definition of a collective understanding of stuttering rising from experience, the opposite dynamic, of singularization, seems to take a vital role in the consolidation of a community of people sharing a common problem. It's through the perception of the existing individual and idiosyncratic ways of living stuttering that PWS relate to the emerging collective.

Second, through this experiential Knowledge, another intended goal was to overcome the knowledge/power relations that usually silences the individual knowledge emerging from everyday pragmatic experiences of patients, community members, ordinary individuals, when he or she interacts with the collective and institutionalized theoretical and abstract knowledge of scientist, doctors, therapists and others health professional. This was done by focusing on what those who stutter knew about their problem, working collectively on a common understanding of what stuttering meant to them. This allowed the gradual transformation of PWS from silenced victims - either by stuttering or the knowledge/power relations already addressed - to responsible "experts of experience" (Rabeharisoa & Callon, 2004).

On the other hand, through the individual and peer empowerment of PWS resulting from this share of knowledge and practices of stuttering, and through this mutual and collective learning environment, we are observing a rising proto-activism around a "communality" between the participants that is slowly feeding the PSA, strengthening and enabling its institutional building and its political and epistemic empowerment. This is being done by the gradual capability of developing a co-production of the agenda of discussion of what is important and relevant when talking about stuttering. It's not

innocent the fact that these 3 different modalities of relational spaces are gaining significant relevance in the overall discussion of stuttering in Portugal.

Conclusion

Is important not to forget that the rise if this proto-activism is taking place through an intense engagement with knowledge, more accurately between an experiential knowledge and a political awareness - that are taking form simultaneously - and the different scientific and medical bodies of knowledge. For the PSA, this results in a mode of activism made in the intersection of science and politics, in a more informed, robust and far-reaching mode of activism. This has been recently conceptualized as "evidence-based activism" (Rabeharisoa *et al.*, 2013). With this notion of evidence-based activism, the authors wanted to capture the innovative aspects that features this new organizational knowledge-related activities developed by CSOs related to health. Instead of mobilizing knowledge as a resource for grounding political claims, knowledge is at the very center of this mode of activism (*Idem*: 7). Through this mode of activism the different bodies of knowledge are constantly confronting each other, being tested in social worlds different from those who produce them, with other validation criteria, by new actors with different backgrounds. What counts as a relevant knowledge, what is the very definition of the condition - in our case the definition of stuttering -, and through this the frame of what is in question.

The mobilization and articulation of professional and experiential knowledge is done in order to make the latter relevant, putting those who produce it, PWS, as relevant actors in knowledge production and medical and scientific research in the fields related to stuttering. In this, we can also observe the emergence of new networks of expertise, that articulate experiential and professional knowledge, in the form of new "epistemic communities" as proposed by Akrich (2010), where a new hybrid form of expertise is being created and mobilized for the sustenance of political and scientific claims with the different epistemic actors developing an alliance in that pursuit. This creates new configurations not only of knowledge but also of meaning and perception for all those involved, transforming not only the way PWS live and understand stuttering but also clinicians and the professionals involved. The success of this knowledge centered mode

of activism will be measured by the actual capacity of PWS, through the Portuguese Stuttering Association, to influence the definition of the research agendas on stuttering.

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