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Stuttering as a boundary object: reflections on the development of a collaborative device

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1. Introduction

STS have shown the virtues in moving from Public Understanding of Science to Public Engagement with Science, from the communication of scientific knowledge to a lay homogeneous public to the promotion of co-production of knowledge experiences through the involvement of Civil Society Organizations (CSO) in research projects.

"Collaborative participatory research" or "community based participatory research" reveal some of the complexities of science and society relations. Throughout this paper I will reflect on how these projects could stimulate a radical co-presence among different epistemic actors in order to overcome the deficit model and the related power/knowledge relations. To this purpose, the promotion of an ecology of knowledge (Santos, 2006), based on a non-disqualifying relationship of mutual recognition between knowledge will frame this reflection, thus testing the hypothesis that these research models allow the emergence of "nonscientists" as active participants in scientific research projects

The collaboration between the Portuguese Stuttering Association (PSA) and the Centre for Social Studies (CSS) being held under the Biosense project will be at the core of this article.

2. What does it mean to collaborate?

Collaboration refers to situations 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). The model of collaboration here considered includes not only academic actors - given the internal diversity of the scientific community - but also representatives of CSO's.

Therefore, our focus of attention is directed to the analysis of the conditions necessary for a situation of non-reproduction of the knowledge/power hierarchical relations that traditionally shape the interactions between scientists and citizens. Only then citizens can emerge not as objects of research, but as active partners in the

production of knowledge, contributing actively in all stages of research including the use of its outcomes.

This seems to imply that the knowledge drawn from CSO should be recognized as a legitimate and relevant epistemological resource to the process of knowledge production. There is the need to create a collaborative device that allows a dialogue based on horizontal and not disqualifying relations between common sense and scientific epistemologies.

This raises questions concerning the classic epistemic distinction between experts and lay people, and to how we can stimulate these dialogues between different epistemic communities in a situation of collaboration.

3. Creating a collaborative device

The starting point was the recognition of an equal capacity to produce valid knowledge by all those participating. Thus, this epistemological parity does not come as a final goal, but as an initial assumption for the creation of this collaborative device. This postulate assumes no initial distinction between scientific knowledge and common sense, considering this distinction as the result of organized social practices. On the other hand, assumes that reality and the knowledge produced about it is the result of the action of individuals and of their concrete experience of the world.

The collaboration between CSS and PSA started with a preliminary meeting arranged with the intention of identifying a primary main goal that could leverage the collaboration.

In this first meeting, according to the needs listed by the PSA, a question was identified as being able to trigger the collaborative process: What is stuttering? Stuttering appears as a complex and non-linear entity, not stabilized in the scientific community, whose causes have not been fully identified and whose treatments still lack consensus on its effectiveness. In the Portuguese context this discussion comes at a very early stage, poorly articulated and still very dependent on the Anglo-Saxon tradition.

It was further discussed the scarce and poorly articulated scientific and clinical research conducted in Portugal on this field, and PSA 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 study of stuttering.

It was thus defined the main goal driving the collaboration: the promotion of dialogues and synergies between stutterers, speech therapists, psychologists, experts in neuroscience, linguistics, among others, to stimulate greater research on stuttering, its multiple causes, ways of coping and different legal and clinical frameworks, duly adjusted to the Portuguese cultural and social context, consequently promoting an organizational, epistemic and political empowerment of PSA.

This collaborative device has proven to be pertinent by taking into account a) the difficulties and complexities of this type of alliances between citizens and scientists, and; b) the nature of the object of knowledge itself, stuttering, shared by several thought collectives (Fleck, 1935) claiming a position of epistemological sovereignty. This shared nature of stuttering between different thought collectives suggests that it may be analyzed as a *boundary object* (Star and Griesemer, 1999), an object living in various social worlds that, as such, can serve as a bridge to cross the borders separating them. Boundary objects are plastic enough to adapt to the local needs and constraints, keeping nevertheless a common identity across the various social worlds.

3.1. Institutional platform

From an institutional standpoint, we proceeded to an exhaustive mapping of the actors and institutions considered relevant in the field of stuttering, thus specifying their different approaches, research interests and needs. In doing so we intended looking for potential intersections that could spill over into research collaborations. Simultaneously, parallel meetings were held with PSA in order to provide them a rigorous account of these contacts and to identify new emerging needs and interests for collaboration resulting from this "epistemic contact".

This is a first feature to retain in this analysis: the definition of both problems fueling the collaboration and of motives for the CSO to participate in such collaborations are part of an iterative process that seems to be essential not only for the development and maintenance of these collaborative devices but also to ensure the social relevance of the outputs. This seems to stem from the difficulty that in the Portuguese context many CSO find, as they engage in these of collaborative alliances,

to define needs and problems that could be addressed within these alliances. Comparative analysis to other national realities is necessary.

Therefore, it seems to be only in the dialogical setting of the collaborative device and through the dialogue maintained with the other epistemic actors that both the problems that can be addressed and the means for doing so are identified. It is essential to put forward an iterative process of identification of the relevant actors and thereby of potential problems and needs, opening therefore the range of possible actions to be developed. On one hand, identify what are the needs of the different organizations and, on the other, diagnose what synergies can be forged in the course of collaboration in order to create knowledge gains for all those involved.

3.2. Identities, knowledge and objects

Simultaneously a strategy of action directed specifically for people who stutter (PWS) aims for their epistemic empowerment. The objective is to foster an understanding of stuttering rising from PWS, allowing their emergence as "experts in experience". Thus, spaces were created where PWS can get together and share experiences in a process that aims trough the establishment of a community of practices (Lave and Wenger, 1991) around stuttering, the construction of an alternative narrative and a new collective identity.

In this sense a Google Group on stuttering was created and provided support in the organization of self-help groups. If self-help groups serve exclusively as face-to-face meeting points for PWS to get together and talk, the Google Group aims to provide an online platform for reflection and debate on stuttering, looking in addition to foster dialogue between PWS and speech therapists, psychologists and other experts working on stuttering.

The Google Group has facilitated the sharing of testimonies and narratives about personal experiences of stuttering and is now beginning a critical analysis of them, departing from a logic of simple accumulation of testimonies to a logic of critically theorizing about them, with a discussion concerning common features, experiences and shared perceptions, reflecting on new ways of understanding and experience stuttering in order to combat stereotypes and discrimination. This has allowed the perception of stuttering not as an individual problem but as a collective and social problem. On the other hand, has given rise to a collective process of

intersubjective reconfiguration of the stuttering entity. This can be viewed as a phenomenological reconstruction of stuttering. We have witnessed the consolidation of a new typification of stuttering, of what it means to be a stutterer, on how to communicate through stuttering and in the numerous communicative settings, new coping strategies, etc.

Another relevant question concerns the fact that the construction of these alternative and emancipatory identities of PWS as "experts in experience" is taking place dialogically, in dialogue with other forms of knowledge and other identities that interact with stuttering. Thus, there aren't just PWS who are reconstruction their identity through these devices. Also speech therapists, psychologists and others, through the contact and interaction with these new narratives of stuttering, are being redefined as experts on stuttering. Their perception of stuttering as an object of knowledge and intervention is reconfigured, and thus, so their experience as professional dealing with stuttering. We can say that identities, knowledge and objects are co-constructing relationally through dialogue in the context of our collaborative device.

4. Final remarks

The creation of the collaborative device around stuttering, by taking as its constitutive premise the equal capacity of all stakeholders to produce knowledge about stuttering, raises the following question: if everyone is equally capable of producing knowledge about stuttering, which of such knowledge is relevant to participate in the collaborative device? The definition of those epistemologically relevant cannot be made through the use of the classical distinction between experts and lay people since all participants are establish as experts and, therefore, as having a legitimate and relevant knowledge on the subject of collaboration. Perhaps the analysis of the effective benefits those expertize bring to the life of PWS can serve as a possible approach to evaluate their social and epistemic relevance.

This emerging community of practices appears to be fostering the creation of a strongly situated and experimental knowledge, setting a form of hybrid and heterogeneous expertize where all are simultaneously co-constituted as both experts and laymen and thus equally legitimated to interact in a horizontal and non-disqualifying dialogue.

The constitution of this collaborative device has enabled us to analyze how each participating subject is constituted both a layman and an expert on stuttering. The sharing of the same object by different communities, the overlapping epistemological sovereignties and hence the existence of partial jurisdictions can promote cooperative relationships but also of competition and conflict. This, rather than being taken as problematic, should be used as a resource for the development of any collaboration. Each thought style (Fleck, 1935), not producing a totalizing knowledge about stuttering, emerges always as partial knowledge, creating shadow zones and, as such, helping to delineate the outlines boundaries of the known object. The partiality is revealed in the contacts with those other epistemologies and the knowledge about the object of collaboration is magnified continuously when confronted with new forms of ignorance about it.

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