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Patient organizations as emerging actors in the health arena: the case of Portugal

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Abstract

Patient associations and organizations have emerged in different parts of the world as central actors in the opening up of new spaces for participation and deliberation in the field of health, developing innovative ways of intervention, mediating between heterogeneous participants in the health field, promoting and organizing platforms and coalitions on a national and international level and taking an active role in areas previously reserved for specialists and professionals, such as research. This article presents research currently underway into patient associations in Portugal, as part of wider research into new actors in the health arena in the European context.

Keywords

Patient associations, health, research, intervention, Portugal

During the past decades, patient associations and organizations have appeared in different parts of the world – such as Europe, North America and Latin America - as new collective actors playing a central role in the transformation of the health field. This transformation includes the opening up of new spaces for participation by patients and by those providing care outside of the professional medical and nursing environment, working to protect rights and in particular the effective rights of patients in access to healthcare. In addition, patient associations and organizations have developed innovative ways of mediating between heterogeneous participants in the health field, such as professionals, healthcare institutions, government and policymakers, researchers and research institutions in biomedicine and public health, non-conventional care providers and the pharmaceutical industry (RABEHARISOA, 2003; 2006; RABEHARISOA et al., 2002; BARBOT, 2002; GAUDILLIÈRE, 2002; DODIER, 2003; BROWN et al., 2005).

The promotion and organization of platforms and coalitions between associations and between these and other actors, both in each country and on a transnational scale – as is the case in the European Union - represent one of the most effective ways of increasing the visibility and the capacity of patient associations as political actors. Another characteristic of the associations is their involvement in activities which are traditionally considered as the exclusive domain of researchers, specialists and professionals, such as biomedical research. Many associations have tried to actively intervene in the redefinition of research priorities, in the organization of clinical trials, in securing funding for research about rare or chronic diseases or in the production of knowledge about situations and conditions about which there is little or no scientific production (EPSTEIN, 1996; 2000; RABEHARISOA et al., 2004).

The research which is outlined here is part of a wider project (MEDUSE: Governance Health and Medicine: Opening Dialogue between Social Scientists and Users), financed by the European Commission in the context of the 6th Framework Program. It is a partnership between the École des Mines in Paris (France), Lancaster University (United Kingdom), the National Center for Scientific Research (France), the University of Liège (Belgium) and the Center for Social Studies of the Faculty of Economics at the University of Coimbra (Portugal). The central objective of the MEDUSE project is the promotion of dialogue between social scientists and non-academic actors in the European health arena (RABEHARISOA et al., 2006). The work being done by the Center for Social Studies seeks to inventory and analyze the scenario of patient and/or disabled people's associations in Portugal and the comparison with France. A second task involves collaboration with the associations in the organization of a European space of dialogue and deliberation on health policies.

The two starting points for this research are firstly the relative historical weakness of patient associations in Portugal (a situation which also extends to all associative activity in the country) (SANTOS, 1994) and secondly the recent emergence of new associations and movements which have asserted themselves as protagonists in the health arena. The lack of systematic information for the identification and delimitation of this universe made it necessary to establish a database about the associations and their characteristics as well as carry out qualitative research to reach a detailed characterization of their activities. As they are an emerging phenomenon, it is not possible to define patient associations a priori, and a three-step methodology therefore had to be developed: preliminary research into internet websites, information published in the media and a "snowball" sample based on the identification of privileged informants, both members and leaders of associations as well as professionals and researchers involved with them, with the aim of establishing a database. So far 101 associations have been identified and characterized. In the second stage, a questionnaire was sent to these associations, and 43 responses were received, providing detailed information about the respondents in relation to when they were founded, how they are organized, their leadership, the number of members, the activities carried out, publications and other materials, involvement in research, national and international partnerships, sources of funding and the means used to access and disseminate information. Finally, two focus groups were carried out with representatives of 11 patient associations which were selected in advance in order to give the maximum diversity in their characteristics, composition and objectives. This selection was made based on the information collected in the database.

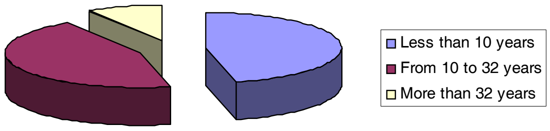
From the preliminary analysis of the inquiry it can be confirmed that a resounding majority (90.8%) of associations currently active and which responded to the research were created after the return to democracy in Portugal, that is, between 1974 and 2006, with around 50% of them having been in existence for more than ten years.

It is also relevant that around half (48.6%) have less than 300 members and approximately two thirds (67.6%) have less than 500 members, with the full range going from 12 to 12,549 members.

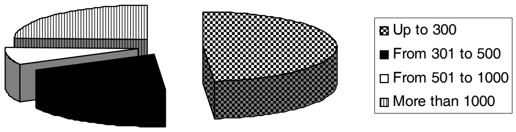
The information included in the database is currently being explored, so as to enable a detailed characterization of the universe of patient associations in Portugal.

The focus groups concentrated on three important themes: the new social and political role of patient associations; the internationalization of patient associations, especially in the European context; and finally the involvement of patient associations in

Graphic 1 - Associations of patients by years of existence



Graphic 2 - Associations of patients |by numbers of members



Source: MEDUSE project database

research and the reconfiguration of the practices of health professionals and institutions. The participants were asked to express their positions in relation to these three themes. The design of the focus group format enabled a dialogue among the participants to help to clarify the diversity of their positions, where they agreed and where they disagreed. Each of the focus groups was moderated by a member of the research team and recorded and transcribed.

It is possible to identify four preliminary results of the research. The first one concerns the still limited collaboration between associations despite a strong convergence in some of their objectives, namely defending the right to health before the state and guaranteeing the provision of adequate care and access to medication for patients suffering from chronic diseases or disability. A second result is the strong internationalization of a large part of the associations, which in some cases were even set up with support from international federations or platforms and based on models inspired by peers in other countries. In third place it is important to register the recognition of the importance of research and collaboration with professionals and researchers, although the scarce financial and organizational resources and reliance on volunteer work which are a feature of the majority of the associations often prevent this recognition from becoming effective involvement in such activities. However there are some cases of collaboration with research institutions around rare or congenital diseases for which treatment is not available and where much of the specialized knowledge about the disease is crucially reliant on the information generated through reports or accounts of the experience of living with the disease or caring for those affected by it. Finally there is evidence of associations which defend and promote what could be described as the demedicalization of situations amongst those subject to the authority and competency of health professionals. This is the case for example of associations who defend the humanization of childbirth and infertility treatment as well as associations of disabled people who try above all to promote the question of disability as a problem of the recognition of rights linked to difference. One situation which requires a specific mention is that of the problems linked to mental health, in which there is a discernable tension between the “medicalizing” approach which demands the widening of access to care and medication and the “demedicalizing” approach which tries to deal with these situations by refusing to consider them as illness.

This research process has evolved into a kind of participatory action research (FALS-BORDA, 2001; AUGUSTO et al., 2005), largely due to the way in which the project itself served as a platform for meeting and dialogue for the actors involved, with the researchers acting as mediators. That is why the research carried out in Portugal has led to a question about the significance of dialogue between social scientists and other actors, what are the spaces, resources and procedures through which this dialogue takes place, and how it is understood and appropriated by participants. In any area such as health in which the production of knowledge cannot avoid dealing with its normative implications, the role of social scientists cannot be that of distant observers. It will have to be rethought as a process of engagement which links the rigor of collaborative knowledge production with a normative position which is in solidarity with those fighting for their rights, for recognition and for the construction of knowledge which is socially responsible and relevant.

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João Arriscado Nunes is associated professor at the School of Economics in the *Universidade de Coimbra* and researcher of the Social Studies Center, a laboratory associated to the same institution. Besides that, he is co-coordinator of the Center of Studies on Science, Technology and Society and of the Doctorate Program in Governing, Knowledge and Innovation. In the Social Studies Center, he is a member of the team at the Center of Studies on Democracy, Multicultural Citizenship and Participation. His main interests in research include social studies of biomedicine and of sciences of life and public participation in areas involving science and technology. During the last years, he took part and coordinated teams in several national, European and international research projects. Currently, he integrates and coordinates the Portuguese teams of the research projects "Researching Inequality through Science and Technology" (ResIST), "Governance, Health and Medicine: Opening Dialogue between Social Scientists and Users" (MEDUSE) e "Deepening Ethical Engagement and Participation in Emerging Nanotehnologies" (DEEPEN), all financed by the European Commission. He is also the responsible researcher of the "Biographies of Objects and Discovery Narratives in Biomedical Sciences: The Case of the Helicobacter Pylori" project, and a member of the team at "Science in Parliament: A Study on the Border between Science and Politics" project, both financed by the Fundação para a Ciência e a Tecnologia [Foundation for Science and Technology] (Portugal). He integrates the European Neuroscience and Society Network (BIOS). He is co-organizer of "*Enteados de Galileu: A semiperiferia no sistema mundial da ciência"* [Galilean Stepchildren: The semi-area in the world system of science] (with Maria Eduarda Gonçalves, 2001) and *Reinventing Democracy: Grassroots Movements in Portugal* (with Boaventura de Sousa Santos, 2006).

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