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When rarity is an asset: political activism for the rights of persons with rare diseases in the Brazilian Unified National Health System

Quando ser raro se torna um valor: o ativismo político por direitos das pessoas com doenças raras no Sistema Único de Saúde

Cuando la rareza es un activo: activismo político por los derechos de las personas con enfermedades raras en el Sistema Único de Salud brasileño

Martha Cristina Nunes Moreira [1]
Marcos Antonio Ferreira do Nascimento [1]
Dafne Dain Gandelman Horovitz [1]
Antilia Januaria Martins [1]
Marcia Pinto [1]

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[1] *Instituto Nacional de Saúde da Mulher da Criança e do Adolescente, Fundação Oswaldo Cruz, Rio de Janeiro, Brasil.*

Correspondence
M. C. N. Moreira
Departamento de Ensino, Instituto Nacional de Saúde da Mulher da Criança e do Adolescente, Fundação Oswaldo Cruz.
Av. Rui Barbosa 716, 2º andar, Rio de Janeiro, RJ 22250-020, Brasil.
moreira@iff.fiocruz.br

Epidemiological criteria are used to determine when a disease is rare. Although the rates vary, studies commonly adopt a threshold of 65 cases per 100,000 inhabitants to define any single rare disease. However, when taken all together, rare diseases affect an estimated 6 to 8% of the population, according to a European study [1,2,3,4]. The expression "rare disease" attributes a positive dynamism to the fact that each group of persons living with a given disease varies greatly, with the rate for a single disease considered low from the epidemiological perspective. When grouped under the heading "rare", these diseases become more visible epidemiologically. This calls attention to the effort to acknowledge the presence of persons living with rare diseases in Brazil, their organization in associations, and their movements as qualified interest groups.

This article focuses not on the distribution of rare diseases in the population, but on the agency of persons organized as interest groups, with mixed interactions [5,6], convening in public places, organizing agendas to occupy the streets [7], academic settings [8,9,10,11], and the legislative and judiciary branches.

The historical background for Brazil's National Policy for Persons with Rare Diseases in the Brazilian Unified National Health System (SUS), launched in 2014 [12], included a public manifesto by various associations in 2011 [13] and the National Policy for Comprehensive Care in Clinical Genetics in 2009 [14]. The most recent spinoff, in 2016, was the Ministry of Health's accreditation of seven reference services in the Distrito Federal, Rio de Janeiro, Porto Alegre (Rio Grande do Sul State), Curitiba (Paraná State), Anápolis (Goiás State), Recife (Pernambuco State), and Santo André (São Paulo State) [15]. The rare disease associations' advocacy merits analysis in light of the social arenas model reviewed by Celina Souza [16].

According to the above-mentioned author, *"In order for a given circumstance or event to become a problem, people need to be convinced that something needs to be done"* [16] (p. 32). Policymakers and decision-makers are encouraged to either ignore or take interest in the problem, in a dynamic relationship with the community of experts. This community includes not only professionals and researchers, but also those with the authority of personal experience, like families. In the case of the needs of persons living with rare diseases, this community consists not only of the individuals themselves and their family members – especially when the person with the rare disease is a child or adolescent – but also the persons that join efforts and resources to see their demands met from a future perspective, that is, *"They're crucial for an idea's survival and success and to include the problem on the public agenda"* [16] (p. 32).

The fact that the associations acknowledge their differences and diverse needs does not prevent the "rare disease" identity from emerging forcefully in the expressions and slogans, for example on World Rare Disease Day 2017: *#somostodosraros* (hashtage "we're all rare" in Portuguese). The expression evokes the value of rarity as a quality, not limited to the disease, but as affirmative action that speaks to those who do not share this experience directly. This exercise of public advocacy constitutes the arena mentioned above, building an expanded visibility and justifying the slogan "*We Do Not Choose To Have A Rare Disease*" as a call for accountability by government (i.e., executive, legislative, and judiciary) to guarantee the right to health. This includes respecting the constitutional right (and quick access) to social benefits, medicines, life support technologies, and rehabilitation services and on-going treatment. Equally important is the rallying cry "*Together We Are More*", reflecting the size in numbers that cannot be expressed when each association only organizes around its own identity and specificity. Combined under the "rare" category, size is achieved and political action draws on various sources of support to streamline communication, organization, and mobilization, especially digital activism [17] in the form of webpages (*Muitos Somos Raros;* http://muitossomosraros.com.br), blogs, and WhatsApp and Facebook (*Somos Todos Raros;* https://pt-br.facebook.com/SOMOS-TODOS-RAROS-174631466265723) groups, which convene some 80 different profiles of associations related to a wide range of diagnoses.

Just as we draw on the social arenas model to shed light on this scenario, we turn to the updated interest groups concept for further theoretical backing. Souza [18,19] assumed that civil society associations, small or large groups of persons meeting around causes related to the experience with their disease, could be seen as interest groups working to make their needs visible, orienting political action. The author did not focus only on interest groups as major traditional players like trade unions, business associations, and corporations. Following the clues by Offe [20], it is important to examine how interest groups have acknowledged their public status, at three levels of analysis: (a) political will, collective identity, and the group's shared values; (b) the structure of socioeconomic opportunities, which relates to the members' origin and their personal networks of knowledge and influence; and (c) institutional formats and practices that the political system places at the interest group's disposition to ensure their public-interest status, for example, human rights councils, health conferences, and public hearings.

The rare diseases scenario thus features important mixed interaction (in the sense used by Goffman [5]) between peers and informed individuals. In this case, peers are the persons living with the diseases – who can be children, adolescents, young adults, elders, women and men, and blacks and whites, all with varying levels of schooling and income. Informed individuals are those who interact with the above-mentioned peers, linked to the cause due to experience with these persons, with various orders of interest, including family ties, sympathy for (and solidarity with) the cause, professionals, and economic interests. Informed individuals in this scenario of interest groups moving in the arena of rare diseases include the pharmaceutical industry and their representatives with economic ties, health professionals, education, justice, sometimes convened in their corporations and class societies, intervening and collaborating with knowledge and technical expertise.

Interestingly, this mixed interaction incorporates the movement of traditional political actors – the pharmaceutical industry and medical corporations – and "new actors", seen here as the associations of persons with rare diseases, organized on the basis of diagnostic identities but not limited to them.

This movement of associations of persons with rare diseases and families, in these mixed interactions, establishes the networks' format, with contacts, ties, and connections that promote both face-to-face and virtual interactions, expanding the frontiers of identities and geographic limits. The agency of these movements is not reified in the properties of the individual agents. According to the social arenas model, as stated by Celina Souza [16] (p. 32) "*institutions, the social structure, and the characteristics of individuals and groups are crystallizations of the movements, exchanges, and 'encounters' between the organizations in the multiple and interchanging networks that connect or overlap. The focus is on the set of relations, links, and exchanges between organizations and individuals rather than on their characteristics*".

In other words, the growth of this movement of associations of persons with rare diseases, in their mixed interactions, calls for a close look at the exercise of struggle for recognition [21], which calls on actors situated in diverse places and with distinct interests and motivations. This raises the

question of how we can learn about the virtuous circle of civilizing policies that allow the experiences of suffering (disruptive in the difference vis-à-vis the expected standard of health and the body) can reach public channels, rather than subsumed in oppression, pain, and the private world of homes and caregivers, whether lay or professional. In addition, other demands can emerge in the discussion, touching on access to health and rehabilitation, and social and human rights, in a complex network of interactions and interests.

Honneth [21] highlights the possible dialogue between the process of self-fulfillment and contact with other reference persons, in the intersubjective dimension of the encounter and the idea that obstacles can spawn various feelings, expectations, and exchanges between projects. The moral conflicts can allow situations of disrespect to provoke responses that can ensure conditions of self-esteem, self-respect, and self-confidence, empowering the emergence of the subjects of rights. Subjects of rights manage their dependences, building and mobilizing references, deciding on moral questions such as needs for public recognition, access to rights, the fight against stigma, and the creation of alliances.

In relation to the organization in associations of persons with rare diseases and their families, the struggle for recognition occurs when there is disrespect, whether through mistreatment or violation of the individual's honor, rights, or dignity. The appeal to dignity and to the right to life and health emerges in the associations' slogans and reclaims the sphere of acknowledgement that emerges from solidarity, defined as belonging to a field of values and constitutive actions with an intersubjective base of reciprocal recognition. This field creates normative conditions for self-determination and self-fulfillment, based on the mutual acceptance of individual qualities, the basis for self-esteem and confidence in personal achievements, operating in the "*domain of relations of solidariety*" [21] (p. 191-2). According to Gohn, this associative movement allows transforming individuals into subjects [22], contributing to the construction of a political awareness, situated in a virtuous circle, where struggling for their interests can mean recognizing themselves within a collectivity.

In this discussion, the scope may lie in overcoming the antinomies between good and bad objectives, and looking to the countless possible combination that can conjugate exercises of public struggle for rights, by building other narratives about living with a disease and publicizing the experience.

Contributors

M. C. N. Moreira contributed to the study proposal, elaboration, and discussion of the manuscript. M. A. F. Nascimento, D. D. G. Horovitz, A. J. Martins and M. Pinto contributed to the discussion of the manuscript. All authors reviewed and approved the final version.

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